

POLICY AND PROCEDURE

Policy Number: HS-XXXX

Index Title: Physicians

SUBJECT: Guidelines on Life-Sustaining Treatment

DATE: xx/xx/2012

I. POLICY

It is the policy of (Name of health system or facility) to provide quality medical care to its patients with the objective of enhancing the quality of life and conforming to accepted medical and ethical standards of care. We also recognize the rights of all competent patients to limit, refuse or discontinue medical treatments, including those which are life-sustaining.

II. PURPOSE

This policy sets forth the following:

- Guidelines for refusal of treatment, including life-sustaining treatment.
- Guidelines for implementation of a patient's advance directive for health care.
- Guidelines regarding decision-making for treatment, including life-sustaining treatment in cases where a written advance directive does not exist.
- Guidelines concerning out-of-hospital do-not-resuscitate orders.
- Guidelines regarding decision making for patients who have not designated a substitute decision maker.

(Health system or facility name) shall not base the provision of care, or otherwise discriminate against any individual, upon whether or not the individual has executed an advance directive.

III. SCOPE

This policy applies to (define).

IV. PATIENTS' PREFERENCES

Patients may express their desires and preferences about health care treatment in various ways. While patients are encouraged to formally execute living wills and health care powers of attorney, any written or oral statement may provide evidence of the patient's wishes. These statements, however formal or informal, should be considered when the patient is unable to understand the potential benefits, risks and alternatives involved in a health care decision, make health care decisions on his own behalf, or communicate with any other person. They are especially pertinent when withdrawal, withholding or limitation of life-sustaining treatment is being considered.

V. DOCUMENTATION OF DECISIONS TO LIMIT LIFE-SUSTAINING TREATMENT AND ENTRY OF CORRESPONDING ORDERS

A. Orders

1. When it has been determined that a particular life-sustaining treatment is to be limited, the resulting order must be entered into the patient's medical record by the attending physician. Written orders are generally preferred. However, where an attending physician or house staff member is not readily available, for example, in a community hospital, telephone or verbal orders are acceptable if they are issued, documented and counter-signed in accordance with applicable law or regulation. Once the order is issued, it is the responsibility of the attending physician to see that the order and its meaning are discussed with appropriate members of the health care team (including nursing staff and house staff), and documented in a progress note consistent with Section V.B. of this policy. The family or substitute decision maker who participated in the decision-making should also be notified that the order has been entered.
2. Orders to limit life-sustaining treatment should be reassessed as changes in patient status dictate. If orders to limit life-sustaining treatment are to be changed prior to an invasive procedure such changes must be made jointly by the person performing the procedure and anesthesiologist, in consideration of the wishes of the patient and the attending physician before any surgical procedure is to be performed. In some cases, it may be considered appropriate to temporarily discontinue the orders limiting life-sustaining treatment.) See Section VI.A) All decisions must be clearly documented in the patient's progress notes.

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3. Any change in orders to limit life-sustaining treatment must be documented and communicated immediately to the nursing and medical staff. As with the other orders, transfer orders into and out of a unit must include documentation of any existing orders to limit life-sustaining therapy. The limitation of treatment status must be communicated to the nursing staff of the new unit by the responsible nurse from the transferring unit. When patients are moved from a unit for special studies, such as to radiology or for therapeutic procedures (e.g. operating room), the limitation of treatment status must be communicated to the staff of those areas.

B. Progress Notes

A resuscitation status discussion must be recorded in a progress note, which should be entered at the time that an order is written. The note should include the following information:

1. Diagnosis;
2. Prognosis;
3. Patient's wishes (when known) or substitute decision maker's instructions (if the patient lacks decision-making capacity) and family member's wishes (where known);
4. Whatever pertinent consultation or recommendations contributed to the decision to limit life-sustaining treatment; and
5. A description of the patient's decision-making ability at the time the decision was made and the efforts made to ascertain the patient's capacity.

C. Acceptable Orders

1. Order Forms. A Physician Orders to Withhold Treatment Form is available on all nursing units and should be used.
2. Specificity of Orders. Each situation is unique, necessitating individual consideration. Detailed orders are usually required in each case. However, if detailed orders are not provided, to facilitate communication when therapy is to be limited, one of the following categories should be indicated
 - a. No Limitation of Therapy. Patients will receive all medically appropriate interventions, including treatment of cardiopulmonary arrest. All patients are assumed to be in this category unless otherwise noted in the patient's orders and progress notes.

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- b. Limited Therapy. A physician may enter an order to limit specific treatments or diagnostic tests that are no longer medical indicate or desired by the patient (or substitute decision maker). A limited therapy order does not preclude the physician from initiating or continuing other appropriate diagnostic or therapeutic interventions. Nursing and other ancillary staff will continue to provide hygienic care and comfort measures.

Medications, e.g. opioids, may be utilized for comfort care even if they contribute to cardio-respiratory depression. A palliative care consult (where available) may be recommended. A physician wishing to limit treatment in some manner must enter an order to do so and write a progress note detailing specifics and to rationale as outlined above.

3. Out of Hospital Do Not Resuscitate Orders (OOHDNR) and Pennsylvania Orders for Life-Sustaining Treatment (POLST). the following shall apply to patients who enter the hospital whether through the emergency department or otherwise, and who display a properly issued OOHDNR or POLST, as evidenced by a fully executed order, or a necklace or bracelet, in the form prescribed by the Pennsylvania Department of Health:

- Hospital staff are to promptly notify the emergency department physician (for emergency department patients) or in-hospital attending physician (for patients admitted directly to the floor) of the existence of the OOHDNR or POLST.
- Once so notified, it is expected that the emergency department physician or hospital attending physician (as applicable) will assess the patient as promptly as is reasonably possible given the circumstances.
- Unless specifically revoked by the patient or the surrogate *who had requested the OOHDNR or POLST on the patient's behalf*, OOHDNR and POLST will be automatically converted into identical in-hospital orders which will remain in effect until such time as the emergency department physician or attending physician in the hospital (as applicable) assesses the patient and writes new orders. An OOHDNR/POLST represents a patient's wish and a physician order regarding end-of-life care. It should be reversed only in exceptional circumstances.
- Following such assessment, which should include conversations with the patient and/or substitute decision-maker regarding the continuation of the OOHDNR or POLST, appropriate orders (i.e., do-not-resuscitate or full resuscitation) will be issued in compliance with the hospital's policy and procedure. The substance of any conversations with the patient and/or

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Substitute decision-maker should be documented in the patient's chart. If the patient presents to a hospital without adequate evidence of a properly issued OOHDNR or POLST, as identified above, the patient shall be deemed NOT to have an OOHDNR or POLST.

VI. SPECIAL CONSIDERATIONS

A. DNR Status and Operative and/or Interventional Procedures

1. General Statement

Some patients who have chosen not to receive life-sustaining procedures, such as intravenous therapy, ventilator support and cardiopulmonary resuscitation may nevertheless be candidates for invasive procedures intended to promote comfort and quality of life (see Guidelines on Life-Sustaining Treatment, Addendum B, E. 5). Such procedures may involve use of anesthesia that requires temporary use of intravenous access endotracheal intubation and ventilator support.

These medical and surgical interventions can cause a reversible deterioration in the patient's condition or a cardiopulmonary arrest. So while the procedure is intended to promote comfort and quality of life, it may also risk causing the patient's premature death. Accordingly, before such procedures are performed, it may be appropriate, but is not required to temporarily rescind orders to limit resuscitation during the intervention.

The purpose of this section is to: 1) affirm that there are appropriate uses of medical and surgical procedures in persons with "Limited Therapy: status; 2) affirm that it is reasonable to resuscitate such individuals when life-threatening conditions occur as result of a procedure; 3) affirm that it may also be reasonable to NOT rescind a DNR order during a procedure; 4) encourage discussion and shared decision-making, in advance of the procedure, about whether to resuscitate such an individual;) describe how to document the decision; and 6) describe how to resume the previous resuscitation status.

2. Statement of Specific Principles

- a. The general principles outlines in Section IV continue to be relevant. Furthermore, the general principles governing decision making (Guideline on Life-Sustaining Treatment, Addendum B) also continue to be in effect. Specifically:

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1. The patient or substitute decision-maker has a right to make an informed decision regarding modification of resuscitation status during the procedure.
 2. The patient or substitute decision-maker has a right to make this informed decision in collaboration with a physician.
 3. Patients have a right to refuse resuscitation during a procedure.
 4. A physician may decline to perform a procedure if the patient's or substitute decision maker's wishes regarding resuscitation status conflict with the physician's opinion, provided that the physician seeks to transfer care to another qualified physician.
 5. The patient or substitute decision maker has a right to include family members in these dialogues.
 6. Ethics consultations are available in the event of unresolved conflicts of opinion. The corporate Legal Department should also be included in these consultations.
3. Documentation of Decisions and Orders
- a. When a decision is made to temporarily change the patient's resuscitation status during a procedure, the decision and decision-making process should be documented in the physician's progress notes, in the same manner as for the decisions to limit life-sustaining treatment.
 - b. The physician performing the procedure and the anesthesiologist (if one is involved) should document discussing concerning resuscitation status and write appropriate orders on the general surgical/procedural consent form.
 - c. The existing Physician Orders to Withhold Treatment form should be attached to the general surgical/procedural consent form, in order to avoid confusion
4. Resumption of Prior Resuscitation Status
- a. It is presumed that the need for temporary modification of resuscitation status is confined to the time during the procedure (including an anesthesia) and very shortly thereafter. Therefore, the physician should re-order the original resuscitation status as part of the routine post-anesthesia or post-procedural orders, subject to Section VI.A.5, below. If the physician does not do so, the temporary status will be automatically discontinued twenty-four (24) hours after the procedure is completed.

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When the patient is transferred out of the post-anesthesia or procedural suite, the physician should write an order such as: Temporary modification of resuscitation status no longer in effect-“Limited Therapy” status applies.

5. Interim Modification for Medical Complications

- a. Subsequent to completion of the procedure and twenty-four hour post-procedure period, complications may develop. In such circumstances, if a decision was made to temporarily change a code order, it is reasonable to consider delaying resumption of the original resuscitation status during efforts to stabilize the patient. In this event, the physician should discuss the situation and whether to delay resuming the original resuscitation status with the patient or substitute decision-maker. It is prudent to include this possibility in the discussions prior to the procedure, following the Guidelines on Life-Sustaining Treatment.
- b. Occasionally, the physician may conclude that all reasonable and prudent attempts to stabilize the patient have failed. In the event, the physician should discuss the situation with the patient or substitute decision maker about resuming the original resuscitation status.

Again, it is prudent to include this possibility in the discussions prior to the procedure, following the Guidelines on Life-Sustaining Treatment.

B. Pregnancy

General Rule – Notwithstanding the existence of a living will, a decision of a substitute decision maker or direction to the contrary, Pennsylvania law requires life-sustaining treatment, nutrition and hydration to be provided to a pregnant woman who is incompetent and has an end-state medical condition or who is permanently unconscious. This requirement holds unless, to a reasonable degree of medical certainty (and certified on the patient’s medical records by the attending physician and an obstetrician who has examined the patients), life-sustaining treatment, nutrition and hydration will:

1. not maintain the pregnant woman in such a way as to permit the continuing development and live birth of the unborn child;
2. be physically harmful to the pregnant woman; or
3. cause pain to the pregnant woman, which cannot be alleviated by medication.

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Given the complexity of the issues surrounding the withdrawal or withholding of medical treatment from pregnant patients, consultation with the Legal Department and the appropriate Medical Ethics Committee should be obtained.

- C. A pregnant patient's obstetrician may write a prospective order to withhold life-sustaining treatment from a baby following its birth. In such case, the obstetrician must communicate the order to the neonatologist prior to birth. After the birth of the baby, a neonatology attending or fellow, or if the neonate is in the newborn nursery, a private pediatrician, must write the order to withdraw or withhold life-sustaining treatment from a neonate.

SIGNED: _____
(Name) (Title)

ORIGINAL DATE: _____

REVIEW MONTH: _____

SPONSOR: _____

Attachments

STATEMENT OF GENERAL PRINCIPLES

A. Presumption of Favor of Treatment

It is the policy of the institution to provide quality medical care to its patients with the objective of improving health and sustaining life, while practicing in conformity with current ethical and medical standards. However, the professional staff must recognize that patients have the right to make their own decisions about their health care and to accept or refuse treatment, whether life-sustaining or otherwise.

B. Right to Refuse Treatment

Adult patients and emancipated minors with decision-making capacity may decline any treatment or procedure. However, there can be a reluctance to apply this rule to patients who seek to limit life-sustaining treatment. Thus, the guidelines are adopted and promulgated to deal specifically with decisions about life-sustaining treatment.

C. Decisions to Forgo Are Particular to Specific Treatments

A decision to limit, decline, discontinue or otherwise forgo a particular treatment or procedure is specific to that procedure and does not imply that any other procedures or treatments are to be forgone unless a specific decision is also made with respect to those procedures or treatments.

D. Preservation of Patient Dignity

The dignity of the individual must be preserved and necessary measures to assure comfort must be maintained at all times by providing appropriate nursing care, hygienic care, comfort care, and analgesics to all patients, including those who have elected to forgo a specific life-sustaining therapy.

E. Substitute Decision Makers and Patients

In these guidelines the term “substitute decision maker” is defined as specified in this policy. Unless otherwise indicated, the term “patient” includes the substitute decision maker of a patient who lacks decision-making capacity.

F. Availability of Policy to Patients

These guidelines must be available to all patients. Upon admission, all patients will be given a general explanation of the existence and content of these guidelines and will be given the opportunity to name a substitute decision maker in writing. Patients will be able to obtain copies of the guidelines upon request.

G. Judicial Review a Last Resort

Families and health care professionals should work together to make decisions for patients who lack decision-making capacity. Recourse to the courts should be reserved for the occasions when adjudication of incapacity is clearly required by state law or when concerned parties have disagreements that they cannot resolve over matters of substantial import.

GENERAL PRINCIPLES GOVERNING DECISION MAKING

A. An adult patient is defined as any person who is at least 18 years of age. The definition of emancipated minor varies somewhat from state to state and, within states, from context to context. Generally, Pennsylvania law defines emancipated minors as those who have graduated from high school, have married, or have been pregnant. Adult patients and patients who are emancipated minor are presumed to possess the capacity of make health care decisions.

B. Right to Decide and To Be Informed

Each adult patient who possesses decision-making capacity has the ethical and legal right to make decisions regarding his or her health care. Emancipated minors may also make decisions regarding their own care. Furthermore, patients and other health care decision makers have the ethical and legal right to receive adequate information about the indicated diagnostic and therapeutic options (including risks, benefits, nature and purpose of the options), which are reasonably available.

C. Forgoing Life-Sustaining Treatment for Minors

In Pennsylvania, there is neither statutory nor case law that specifically provides or denies minors the right to refuse life-sustaining therapy. However, there is growing recognition by experts, such as the American Academy of Pediatrics, that most minors (over 14) demonstrate a level of mature decision-making capacity that is comparable to that of a competent adult. Usually such minors are in their mid-teens, however they may be younger or older because it is the decision-making capability of the minor, not his or her age, which is most important.

If a minor possesses mature decision-making capacity, it may be appropriate and in the minor's best interest to afford him/her greater participation in medical decision-making regarding the termination of life-sustaining treatment.

When there is a lack of agreement between a minor's wishes and those of the minor's parents or legal guardian a legal and ethical dilemma exists. The parties should consider, among other concerns, the facts and gravity of the situation, the maturity, knowledge and intelligence of the child, and the reasons for and strength of the feelings of other family members. Neither blind deference to parental authority nor overly zealous "child advocacy" will suffice in these instances. The parties should consider availing themselves or consultative help from 1) child psychiatrists, family therapists, or similar professionals skilled in behavioral assessment and counseling, 2) ethics consultants or an ethics committee, 3) other sources of family support, including religious advisors, and, if necessary, 4) the courts.

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Because of the discrepancy between the legal status of minors on the one hand and their cognitive and emotional capacity to make decisions on the other, extra measures should be taken to assist the patient and the patient's family or guardians in decision making

To deal with such conflict, the following guidelines are recommended:

1. The physician should determine the decision-making capacity and maturity level of the minor.
2. To the extent possible, a member of the health care team should inform both the minor patient and the parents or guardians regarding the patient's prognosis, diagnosis, treatment and diagnostic options, risks, burdens and benefits attendant to the available options, and importantly, the physician's recommendations.
3. The health care team should try to share information equally with parents and minors because failure to do so may prevent parent and minors from coming to agreement. Because confidentiality requirements apply, in some circumstances, consent to share information with parents may be needed.
4. The team should consult the ethics consult service to facilitate these deliberations.
5. In almost all such situations, social work and the hospital's Patient Representative should assist supporting the patient and family through this process.
6. When irreconcilable conflict occurs, legal services should be contacted and involvement of the court may be necessary.

D. Informing for Decision Making

1. Decisions about life-sustaining treatment should be made between the patient and/or substitute decision-maker and the attending physician after a thorough discussion of therapeutic options as is reasonably possible.
2. It is the physician's responsibility to provide adequate information about therapeutic and diagnostic options and to discuss them as thoroughly as reasonably possible so that the patient and/or substitute decision-maker may make an informed decision.
3. This information should include the potential risks, discomforts, side-effects, and benefits of treatment, as well as the likelihood of potential outcome, if known.

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4. The physician should, in addition to providing such factual information, also provide advice about treatment.
 5. The physician should:
 - a. Seek to elicit questions from the patient or substitute decision maker;
 - b. Provide truthful and complete answers to such questions;
 - c. Attempt to ascertain whether or not the patient or substitute decision maker understands the information and advice provided; and
 - d. Investigate with the patient or substitute decision maker, the rationale for treatment, including life-sustaining treatment, and how the treatment should be modified to meet the patient's goals. For example, some patients may fear a prolonged existence on a respirator, and yet be willing to undergo a time-limited trial of intubation. The physician should explore which options are most consistent with the patient's goals and document them on the chart.
 6. The patient's understanding of the available options will often increase over time. Therefore, decision-making should be treated as a process rather than an event. In order to provide an opportunity to adequately discuss treatment options with patients before they lose their capacity to decide physicians and nurses should begin the process of informing patients at the earliest possible time, especially upon determination of an end-stage condition.
 7. It is reasonable and appropriate in certain circumstances that a hospital representative inform the patient about financial considerations when requested by a patient or his or her substitute decision maker.
- E. Collaborative Physician-Patient Decision-Making Rights of Physicians and Health Care Workers
1. Decisions to provide and forgo treatment should be made collaboratively.
 2. A patient and/or substitute decision maker should be informed if a physician is of the professional opinion that treatment should be limited.

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3. Where a physician believes that complying with a patient's or substitute decision maker's instructions would be unethical or result in treatment having no medical basis in addressing any medical need or condition of the patient, or where a physician believes that complying with a substitute decision maker's instructions would be contrary to the patient's wishes, then the physician should seek assistance from the Ethics Consultative Service and the Legal Department.
4. If, following such efforts, the attending physician and patient or substitute decision maker do not reach a mutually acceptable agreement, the physician should offer and make reasonable attempts to transfer the care of the patient to another provider who would be willing to carry out the patient's or substitute decision maker's instructions. This should be the final option after attempting to resolve differences with the assistance of the Ethics Consultative Service and the Legal Department. If transfer is not feasible, then the Ethics Consultative Service and the Legal Department should be notified and should participate in any further decision-making.
5. Any non-physician health care worker may decline to participate in the limitation or withdrawal of therapy after providing adequate notice to his or her supervisor.

F. Withholding of Information From Patients (or Substitute Decision Makers)

1. There is a strong presumption that all information needed to make an appropriate decision about health care (including a decision about life-sustaining treatment) should be provided to the decision maker (i.e., the patient or substitute decision maker). When disclosure is purposely limited, the reasons should be documented in the medical record.
2. Information may not be withheld from a patient or substitute decision maker on the ground that its divulgence might cause the patient or substitute decision-maker to decline a recommended treatment or choose a treatment that the physician does not wish to provide.
3. Normally information should not be withheld because of the belief that its disclosure would upset the patient. However, the physician may believe that disclosure would lead to an immediate and serious threat to the patient's health or life. In such cases, the least restrictive degree of withholding should be practiced. Since the process of decision-making will often take place over a period of time, information should be given gradually to the patient, when possible. If patients clearly make known that they do not wish to receive certain information, such information may be withheld provided that patients are informed of their right to have it at any time. The preference should also be documented.

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4. Pennsylvania law requires that substitute decision makers obtain and evaluate information on the patient's prognosis and acceptable medical alternatives regarding diagnosis, treatment and supportive care; required to be provided in connection with the informed consent process; concerning the distinction between curative, palliative and life-prolonging alternative, where applicable; and concerning the distinction between end-stage medical conditions and other concurrent conditions from which the patient may suffer. If a substitute decision maker is unwilling to receive and consider this information, then it may be appropriate to consider one or more replacement decision-makers. In such instances, consultation with the Ethics Service and the Legal Department is recommended.

G. Consultation with Family and Friends

Patients should be encouraged to discuss decisions about life-sustaining treatment with the appropriate family members and close friends. However, professionals should respect the privacy and confidentiality of patients making their own health care decisions and should honor such patients' requests that information (including, but not limited to, medical decisions) be withheld from others. When patients and parents of minor patients wish, providers should honor the family's desire to prevent disclosure of medically related information to the extended family.

H. When to Consult with the Ethics Service and/or Legal Department

1. Patients and concerned individuals should be made aware of the facility's Ethics Service. Patients, family members, substitute decision makers, attending physicians, and members of the health care team may seek a consultation with representatives of the Ethics Service at any time. The goals of such a consultation may include: correcting misunderstanding, identifying appropriate substitute decision makers, helping in the acquisition of needed information, expression of opinions and feelings, clarifying ethical opinions and otherwise mediating and aiding in the resolution of disputes.
2. Physicians and hospital staff are **strongly encouraged** to consult with the hospital Ethics Service and the Legal Department in the following circumstances:
 - a. Ethical issues involving limited life-sustaining treatment for pregnant patients;
 - b. When there is unresolvable disagreement among surrogates and/or patients and/or members of the health care team;

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- c. When application of Pennsylvania law (as described below) appears to result in the designation of one or more health care representatives who do not appear to be the most appropriate individuals to make decisions on behalf of a particular patient;
 - d. Where a health care decision made by one or more substitute decision makers appears to be inconsistent with a patient's expressed wishes, applicable law, or otherwise;
 - e. Where there are conflicts among physicians and/or hospital staff;
 - f. Where no health care agent is designated and substitute decision makers to limit life sustaining treatment on behalf of a patient who is not permanently unconscious or does not have an end-stage medical condition.
- I. No Reasonably Available substitute decision maker. Where, following reasonable attempts, physicians and hospital staff are unable to identify any person who is eligible to serve as a substitute decision maker. In such case, following life-sustaining treatment may be ethically acceptable if all of the following conditions are satisfied:
- a. Reasonable efforts have been made to identify an appropriate person (e.g., a family member or a friend) to serve as a surrogate and those efforts have been unsuccessful.
 - b. There is a consensus among physicians involved with the case that there is no significant chance of meaningful recovery and life-sustaining treatment is of no expected benefit to the patient.
 - c. Conditions (a) and (b) are clearly documented in the patient's chart (progress note).
 - d. There is unanimous consensus at a meeting of the Medical Ethics Committee that: (i) reasonable efforts have been made to identify an appropriate person to serve as a surrogate (ii) considering the patient's condition and prognosis, a reasonable person would conclude that life-sustaining treatment is of no expected benefit and, therefore, not want and (iii) reasonable efforts have been made to determine whether pertinent members of the health care team object to the forgoing of life-sustaining treatment for this patients, and insufficient reasons have been offered to include that forgoing treatment is ethically unacceptable. Each hospital Medical Ethics Committee shall ensure that the attendees at this meeting include representatives from a broad array of disciplines as reasonable determined by the hospital in consultation with the Legal Department.

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- J. Communication and Education. To reduce the risk of the types of situations identified in the preceding subsections H and I, physicians are urged to initiate discussions with patients regarding living wills and health care powers of attorney during initial consultations, annual examinations, at diagnosis of a chronic illness or when in individuals under their care transfer to another health care setting, so that the patients may make known their wishes to receive, continue, discontinue or refuse medical treatment. Physicians should also initiate such discussions, including discussion of out-of-hospital DNR orders, with individuals under their care at the time of determination of an end-stage medical condition. In addition to revealing patients' preferences these discussions will serve to educate patients about health care decision making and the ways to best ensure that such preferences will be honored (i.e., by formally executing advance directives and designating one or more individuals to serve as health care agent).

DECISION MAKING FOR PATIENTS WHO LACK DECISION-MAKING CAPACITY

A. Presumption of Capacity; Decision-Making Capacity in General

1. All adult patients and emancipated minors should be presumed to possess the capacity of make health care decisions, unless demonstrated otherwise and documented in the medical record.
2. A patient's ability to make his or her own decision should be overridden only after a clear demonstration of lack of capacity.
3. A patient's capacity may be questioned. Some conditions which may affect decision-making capacity include: delirium, dementia, depression, mental retardation, psychosis, intoxication, stupor, coma, stroke, traumatic brain injury or possible suicidal intention.
4. Refusal of specific treatment to which most patients would agree does not mean that the patients lacks decision-making capacity, but may initiate inquiry into the matter of such capacity.
5. Lack of decision-making capacity can be a transient condition and can be specific to a particular decision. Therefore, patients who suffer from any of the above conditions may not lack capacity at all times for all purposes and decision-making capacity may need to be reassessed from time to time.

B. Patients Lacking Decision-Making Capacity

1. Patients who lack decision-making capacity have the same substantive ethical and legal rights as patients who possess decision-making capacity. The distinction is that in the case of patients lacking decision-making capacity, their rights may be exercised by a substitute decision maker.
2. Decisions made on behalf of the adult patients or emancipated minor patients who lack decision-making capacity should replicate the decision that the patients would have made had they the capacity to do so. If the patient executed a "living will" health care power of attorney, or any other form of advance directive, this document should serve as strong evidence of the patient's wishes. In the absence of knowledge of the patient's wishes, the decision maker should take into account the patient's preferences and values, if known, and if not known, his or her assessment of the patient's best interests and the following goals and considerations: preservation of life, relief from suffering, and preservation or restoration of functioning.

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3. Decisions made on behalf of minor patients who are not emancipated or who are otherwise unable to make their own healthcare decisions, should be made based on such patients' best interests. Determining best interests involves weighing the benefits and burdens of treatment. The benefits may include prolongation of life (understanding that the continuation of biological existence without consciousness may not be a benefit); improved quality of life after the treatment has been applied (including reduction of pain or disability) and increased physical pleasure, emotional enjoyment, and intellectual satisfaction. The burdens of treatment may include pain; irremediable disability or helplessness; emotional suffering; invasive and/or undignified interventions needed to sustain life; or other activities that severely detract from the patients quality of life.

C. Formal Assessment of Capacity

The formal assessment of capacity is a process that should ordinarily be performed and documented by the attending physician. A psychiatric consultation may be indicated if psychological factors are thought to be compromising capacity; an ethics consultation may also be helpful in determining the patient's' decision-making capacity. However, a consultation is not required if the attending physician is able to assess capacity without it.

D. Selection of a Substitute Decision Maker

1. In general, a patient who, after proper assessment, is determined to lack decision-making capacity, should have a substitute decision maker chosen or designated to make decision on behalf of the patient. Even if a patient has a living will, a substitute decision maker is usually still necessary if the living will fails to give unambiguous guidance in the current circumstances. Possible substitute decision makers should be notified of the presence of the living will. If conflicts arise regarding its implementation and ethics consult and consultation with the Legal Department should be sought.
2. Where the adult or emancipated minor patient, prior to losing decision-making capacity, designated a substitute decision maker either formally or informally, the patient's choice should be respected wherever possible. If more than one substitute decision maker is designated, decisions should be made by consensus of those individuals where possible.
3. Substitute decision makers fall into one of two categories under Pennsylvania law: health care agents and health care representatives.
 - a. Health care agents are individuals designated through a formal health care power of attorney document.

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- b. Health care representatives are individuals who are informally designated by patients through, for example, verbal communication to the attending physician or written communication in a form that does not meet the requirements of a health care power of attorney. Health care representatives may also be designated pursuant to the statutory framework provided by Pennsylvania law (described in section 4 below).

The distinction between health care agents and health care representatives is important because Pennsylvania law affords more authority to health care agents than health care representatives with respect to end of life care decision-making. Specifically, health care agents have the same authority as patients in making decisions about their own health care unless the power of attorney appointing the healthcare agent specifically provides otherwise. The authority of health care representatives to decline life sustaining treatment is limited to patients who have an end stage medical condition or are permanently unconscious. That means that only health care agents may decline life sustaining treatment on behalf of a patient, regardless of a patient's medical condition, if doing so would be consistent with the patient's instructions. Physicians and hospital staff should consult with the Ethics Service and Legal Department in the event that no health care agent is designated and substitute decision makers wish to limit life sustaining treatment on behalf of a patient who is no permanently unconscious or does not have an end-stage medical condition.

4. In the case of a patient who has not designated a substitute decision maker (or if the substitute decision maker is not reasonably available), and for whom more than one individual desires to serve as a substitute decision maker, decisions should be made by consensus of those individuals wherever possible. If the individuals are not able to reach consensus, Pennsylvania law provides a statutory mechanism for selecting the individual or individuals who will serve as health care representatives(s) (described below). **Physicians and hospital staff are strongly encouraged to consult with the Ethics Services and Legal Department prior to applying this statutory mechanism, however.**

The statutory mechanisms provides that any member of members of the following classes, in descending order or priority, who is/are reasonably available, may act as the health care representative(s):

- a. the spouse, unless an action for divorce is pending, and the adult children of the patient who are not the children of the spouse;
- b. an adult child;
- c. a parent;
- d. an adult brother or sister;

Hospital Policy Example F3D

- e. an adult grandchild
- f. an adult who has knowledge of the patient's preferences and values, including, but not limited to, religious and moral beliefs, to assess how the patient would make health care decisions.

Neither a patient's attending physician or other health care provider, nor an operator or employee of a health care provider in which the patient receives care, may be a health care representative unless related to the patient by blood, marriage or adoption.

If more than one member of a class assumes authority to act as a health care representative and the members do not agree on a health care decision, Pennsylvania law provides that the attending physician or health care provider may rely on the decision of a majority of these individuals. Despite this law, however, physicians and staff should strive to build consensus among all class members with regard to health care decisions whenever possible.