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## Introduction

Purpose / Population	Purpose:		
	<ol> <li>Provide a framework for the provision of appropriate end of life (EOL) care including withholding/withdrawal of life sustaining treatment/technology (LST) in compliance with legal and ethical standards of care.</li> </ol>		
	2. Promote respect for the patient's rights in the decision to withdraw/withhold LST.		
	3. Delineate a framework for decision-making in clinical situations in which conflicts exist relating to the initiation or continuation of medical treatment.		
	<ol> <li>Provide guidance to a treating Provider who is contemplating the withdrawal/withholding of LST, including situations where the patient/Surrogate disagree with the medical team.</li> </ol>		
	<ol> <li>Delineate a framework for decision-making in clinical situations in which conflicts exist relating to the initiation, continuation, or termination of medical treatment including LST.</li> </ol>		
	<ol><li>Define the role of Providers, nurses, clinical personnel, patients, family members, and Surrogates in the decision to withdraw/withhold treatment.</li></ol>		
	<ol><li>Provide for the inclusion of patients' spiritual and cultural beliefs in decisions whether or not to withdraw/withhold LST.</li></ol>		
	Population: All Patients		

## Definitions

making

Related to Adult: Any person 18 years of age or older (19 in Nebraska) decision

Advance Directives or Health Care Directives: Documents that express a person's preferences, in advance, relating to the acceptance or refusal of medical care should the person lose medical decision-making capacity. The documents may include a Living Will, Medical Power of Attorney or Pre-hospital Medical Care Directive.

**Code Status:** Refers to the steps to be taken if a patient suffers a cardiopulmonary arrest (i.e. stops breathing or loses pulse). Current Cerner Options are:

- Full code
- DNR/DNI
- Code/DNI
- Intubate/DNR.

Related to decision making, (continued) **Decision Making Capacity (DMC)**: A medical determination regarding the patient's current medical decision-making capability. Any Provider may make a determination of DMC. DMC is decision specific. A person may have capacity to decide about a specific treatment and not about a different treatment and at one time but not another. A patient has DMC if he or she:

- <u>Understands</u> the relevant information about the medical problem;
- <u>Appreciates</u> the significance of the information including the pros, cons and consequences of each choice being offered;
- <u>Reasons</u> through the options and can explain the reasons for choosing and/or rejecting options; and
- <u>Communicates</u> preferred choice(s) clearly and consistently (Applebaum. NEM. 2007)

### DNI: Do Not Intubate

**Do Not Resuscitate (DNR):** For purposes of this policy, DNR encompasses Allow Natural Death (AND).

**Do Not Resuscitate (DNR) Order**: Specific instructions by the Provider regarding the withholding of cardiac or pulmonary resuscitation in the event of a cardiac or respiratory arrest.

**Emancipated Minor**: any person under 18 years of age (19 in Nebraska) who is determined by state law to be free from parental care, custody, and control and capable of making his/her own healthcare decisions. The basis for emancipation is determined by specific state law and may vary from state to state. (See consent policies).

**Guardianship**: A legal relationship created when a person or institution is assigned by the court to make decisions on behalf of minor children or incompetent adults. The court determines the authority and responsibilities of the guardian as defined in the guardianship documents. The guardianship may or may not include authority to withhold or withdraw LST. Only the court can revoke the guardianship, which is necessary to restore the rights of the individual to make his/her own health care decisions.

Health Care Power of Attorney (HCPOA) (may be known as Medical Care Power of Attorney (MCPOA)): A written statement signed by an adult (called the principal) naming another adult person to make health care decisions on behalf of the principal in the event the principal lacks decision-making capacity. The HCPOA must meet requirements of state law.

Related to decision making, (continued)	Living Will (may be known as Instructions for Health Care, Provider Orders for Life Sustaining Treatment (POLST), Medical Orders for Life Sustaining Treatment (MOLST), or Wyoming POLST (WyoPOLST)): A written statement tha is intended to guide or control the health care treatment decisions that can be made on the person's behalf. The language of the Living Will may vary and some Living Wills specifically do not authorize the withholding/withdrawal of food/fluids. The Living Will must meet requirements of state law.		
	Newborn: A minor less than one year old.		
	<b>Provider:</b> For purposes of this policy, Provider includes credentialed Providers and advance practice providers who are involved in end of life decisions, where permitted by Medical Staff Rules and Regulations.		
	<b>Surrogate Decision Maker or Surrogate</b> : A person authorized to make health care decisions for a patient by a Health Care Power of Attorney, a court order or by provisions of state law. See policy: <u>Surrogate Decision Makers</u> .		
	Withdrawal/Withholding of life sustaining procedures: The withdrawal/withholding of LST includes Do Not Resuscitate (DNR), Do Not Attempt Resuscitation (DNAR), or Allow Natural Death (AND) orders and includes:		
	<ul> <li>No basic cardiopulmonary resuscitation; i.e. no mechanical chest compression and no mouth-to-mouth or bag valve mask ventilation;</li> <li>No endotracheal intubation;</li> <li>No defibrillation;</li> <li>No pressors;</li> </ul>		
	· · ·		
Ethical principles and concepts	<b>Autonomy</b> : Respect for the individual's right to self-determination and his/her ability to make decisions with regard to his/her own health and future. The individual has the right to refuse treatment to the extent permitted by law and to be		

ability to make decisions with regard to his/her own health and future. The individual has the right to refuse treatment to the extent permitted by law and to be informed of the medical consequences of such action. Autonomy does not include the ability to demand treatments that are not being offered by the medical teams.

**Beneficence**: The ethical principle of "doing good". Such actions are done for the benefit of others to promote good and minimize burdens.

**Brain Death**: is the permanent absence of all brain functions, including those of the brain stem. The person is legally deceased when brain death is declared (except in NJ where a legal exception exists). Also known as Death by Neurologic Criteria (DNC). (See Determination of Brain Death section of the <u>Anatomic Organ</u> <u>Donations: Organ, Tissue, and Eye Procurement</u> Policy.)

**Imminent Death**: Death that is expected to occur within hours or days based on the person's condition, disease progression and symptom constellation.

Ethical principles and concepts, continued	<b>Justice</b> : It is often regarded as being synonymous with fairness and can be summarized as the moral obligation to act fairly when evaluating competing demands. In health care, it can be subdivided into three categories: fair distribution of scarce resources (distributive justice), respect for people's rights (rights based justice) and respect for laws (legal justice).
	<b>Objection of Conscience</b> : the refusal of a healthcare Provider to participate in a medical treatment (or removal of treatment) because of deeply held personal beliefs.
	<b>Non-maleficence</b> : To "do no harm." Providers must refrain from providing ineffective treatments or acting with malice toward patients.
States of illness	<b>Life-threatening Illness</b> : One where there is a high probability of death due to severe illness, but there is also a chance of long-term survival.
	<b>Persistent Vegetative State</b> : A vegetative state present at 1 month after acute traumatic or non-traumatic brain injury, and present for at least one month in degenerative/metabolic disorders or developmental malformations. Patients diagnosed with persistent vegetative state show:
	<ul> <li>No evidence of awareness of self or environment and inability to interact with others;</li> <li>No evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli</li> <li>No evidence of language comprehension or expression;</li> <li>Intermittent wakefulness manifested by the presence of sleep-wake cycles;</li> <li>Sufficiently preserved hypothalamic and brainstem autonomic function to permit survival with medical and nursing care;</li> <li>Bowel and bladder incontinence; and</li> <li>Variably preserved cranial nerve (pupillary, oculocephalic, corneal, vestibulo-ocular, gag) and spinal reflexes.</li> </ul>
	<b>Permanent Vegetative State</b> : A persistent vegetative state becomes permanent twelve months after traumatic brain injury and 3 months after non-traumatic brain injury. The chance of recovery after these periods is exceedingly low, and recovery is almost always to a severe disability.
	<b>Terminal Illness</b> : Terminal condition is one caused by disease or injury that is irreversible and incurable and expected to result in the death of the patient.
	Continued on next page

**Treatment** measures Artificial Nourishment and Hydration: A medical procedure whereby nourishment or hydration is supplied through a tube inserted into a person's nose, mouth, stomach, or intestines, or nutrients or fluids are infused intravenously into a person's bloodstream.

**Comfort Care Measures**: Clinical interventions designed to alleviate pain and suffering, which usually accompanies expected death.

**Hospice Care**: Care designed to give support to people in the final phase of a terminal illness that focuses on comfort and quality of life. Care is provided by a team of health care professionals and volunteers who give medical, psychological, and spiritual support, generally to patients with a life expectancy of six months or less.

**Life-Sustaining Treatment (LST)**: any therapy or intervention which uses mechanical or other artificial means to sustain, restore, or supplement a vital function. Life-sustaining treatment includes, but is not limited to:

- Ventilator support
- Vasopressor support
- Dialysis
- Antibiotics
- Cardiac devices

**Palliative Care**: Specialized medical care for people living with serious illness. Palliative care focuses on providing relief from the symptoms and stress of a serious illness with a goal of improving quality of life for the patient and the family.

# Policy

Decisionmaking process

### DECISION-MAKING PROCESS FOR WITHDRAWING/WITHHOLDING OF LIFE-SUSTAINING TREATMENT

- 1. In the absence of a Do Not Resuscitate (DNR) Order to withdraw/withhold LST, cardiopulmonary resuscitation (CPR) will be initiated when a patient experiences acute cardiac or respiratory arrest.
- 2. When organ donation is being considered with the Organ Procurement Organization (OPO), LST will be continued after the determination of death in accordance with the directions of the OPO.

Decision- making process, (continued)	A decision to withhold/withdraw one kind of LST does not imply that the patie foregoing any other forms of treatment. Specific resuscitative measures to be withheld should be discussed and documented on the medical record if they differ from the definition of DNR. The decision to withdraw/withhold LST neve precludes the provision of treatments to relieve pain and suffering associated with the patient's medical condition.	e er
	Orders to withdraw/withhold LST will be reviewed with the patient or the patien Surrogate Decision Maker. The medical record will reflect whether such order are to be suspended:	
	<ul> <li>during surgery and, if so, for what period of time peri and post-operatively</li> <li>at the time of admission to a behavioral health unit and, if so, will reflect whether such orders are to be suspended during the admission.</li> </ul>	
	DNR orders should be reevaluated periodically, including during each admiss	sion.
	Emergency Department will comply with the resuscitative directions on an apparently genuine Pre-hospital Medical Directive/MOLST/POLST/WYoPOLS form signed by a licensed health care Provider. In particular – Arizona has a "Prehospital Medical Care Directive (Do Not Resuscitate)" printed on bright orange paper.	
	If a Provider believes that appropriate end of life care indicates the withdrawal/withholding of LST or the patient or Surrogate Decision Maker requests the foregoing of LST, the Provider and Surrogate Decision Makers s discuss the medical situation, and consensus shall be obtained before the Provider can order the withdrawal/withholding of LST.	shall
	If the patient, the Surrogate Decision Maker, or family member approaches a member of the health care team regarding the withdrawal/withholding of LST information will be conveyed to the Provider to discuss the situation and the conversation will be documented.	
	If a Provider and the patient and or Surrogate disagree on the use of LST, the Provider and Surrogate Decision Makers shall discuss the medical situation a attempt to reach an agreement. Documentation of this discussion shall be no in the medical record. See Subtopic: Decisions Contrary to Provider Judgme or Personal Ethics if consensus if not reached.	and oted
	The concerns of the patient and family regarding dying and expression of grie by the patient and family should be acknowledged. Palliative Care, Hospice, Social Services, and the chaplain may be used as resources.	
	Information on the cultural aspects of withdrawal of care may be taken into consideration.	
	Allied Health Professionals may order code status under the direction of a responsible Provider, who must co-signed the orders within 24 hours.	

13. This policy does not apply to Behavioral Health Units, as end-of-life care is not provided in these areas.

Policy, Con	ued
Determination of decision- making capacity	<ol> <li>A Provider will determine if the patient has Decision Making Capability (DMC) before foregoing treatment based upon the patient's own request or consent.</li> </ol>
	2. The Provider must document the basis for his/her determination that a patient lacks DMC in the medical record. This includes circumstances where the severity of the patient's illness or the use of analgesic, psychotropic and/or sedation medications that cannot be safely withdrawn is the basis for the patient's lack of capacity.
	<ol> <li>Where DMC is questionable and the patient is on sedation medications that can be safely withdrawn, such medications must be withheld or reduced to allow a determination of DMC.</li> </ol>
	<ol> <li>If the Provider has questions about the patient's DMC, a second medical opinion is to be sought from another Provider (not necessarily a psychiatrist) who must also document the basis for his/her opinion in the medical record.</li> </ol>
Patient with decision- making capacity	<ol> <li>If the patient has DMC, the Provider may forego treatment with the informed consent of the patient.</li> </ol>
	2. If the patient is severely depressed, addressing depression is strongly urged before acceding to a patient's request to forego treatment when treatment for the clinical condition has reasonable chance of cure or of accomplishing a significant period of good-quality life.
	3. If the patient is pregnant and the health of a fetus would be imperiled by an order to forego treatment of the mother, Risk Management must be contacted.

Patients without decision- making capacity	1.	<b>Minors</b> : While a minor lacks legal decision-making capacity, children who understand their medical condition, treatment options and risks and benefits of treatment OR children over the age of 14 should be involved in decisions regarding the withdrawal of LST. Risk Management must be consulted if the parent is not acting in the best interest of the child in the opinion of the Provider.
	2.	Adults and Emancipated Minors: If an adult or emancipated minor patient does not have capacity, the record is reviewed for HCPOA or guardian documents. Except in emergency situations, the HCPOA may not be implemented unless the document has been provided. If no Surrogate Decision- Maker is located, the Provider and facility must use reasonable efforts to identify, locate and consult with statutory Surrogates.
	3	<b>Pregnant Patients</b> : If the patient is pregnant and the health of a fetus would be

3. **Pregnant Patients**: If the patient is pregnant and the health of a fetus would be imperiled by the decision-maker's request to withdraw treatment of the mother, Risk Management must be contacted.

Patients without decisionmaking capacity, continued 4. Surrogate Decision-Maker Responsibility: In reaching his/her decision, the Surrogate must act in accordance with the patient's wishes as expressed in the Health Care Directive. If the Directive does not provide sufficient guidance, the Surrogate should base the decision on his/her knowledge of the patient's values and preferences and should attempt to reach the decision that the patient would make if the patient had DMC. If no reliable evidence of the patient's wishes exists, the Surrogate should act according to the Surrogate's good faith belief as to what is in the best interests of the patient. If the Surrogate Decision-Maker chooses a course believed by the Providers to be clearly contrary to the patient's wishes or the best interests of the patient, Risk Management must be contacted.

### 5. **Provider Surrogate**: See policy: <u>Surrogate Decision Makers</u>

**In Arizona:** If a Provider is acting as a patient's Surrogate, the Provider must "consult with and obtain the recommendations of an institutional Ethics Committee/Clinical Ethicist" to make health care treatment decisions. Only if this is not possible, the Provider "may make these decisions after consulting with a second Provider who concurs with the Provider's decisions." (AZ Statute 36-3231)

In Colorado: Colorado Statutory Surrogates: (See policy <u>Colorado Advance</u> <u>Health Care Directives</u>)

- An attending Provider may designate another willing Provider to make health care treatment decisions as a patient's proxy decision-maker if:
  - After making reasonable efforts, the attending Provider or his or her designee cannot locate any interested persons, or no interested person is willing and able to serve as proxy decision-maker;
  - The attending Provider has obtained an independent determination of the patient's lack of DMC by another Provider; by an advanced practice nurse who has collaborated about the patient with a licensed Provider either in person, by telephone, or electronically; or by a court;
  - The attending Provider or his or her designee has consulted with and obtained a consensus on the proxy designation with the medical Ethics Committee/Clinical Ethicist of the health care facility where the patient is receiving care; and
  - The identity of the Provider designated as proxy decision-maker is documented in the medical record.
- 6. **Provider Responsibility to Surrogates**: The Provider must discuss the patient's medical situation with the Surrogate Decision Maker in the same manner that the Provider would with a patient who has DMC. The Provider must also act in accordance with the instructions of the Surrogate unless instructions are contrary to a valid Health Care Directive that has been provided to the hospital.

Minors

1. A DNR order may not be implemented for a minor not under juvenile court jurisdiction before the Provider has communicated with at least one of the minor's parents/legal guardian:

- The minor's care plan, including implementing a DNR order and what the order means;
- The parent's right to request that the minor be transferred to another facility; and
- The parent's right to seek a court order blocking the implementation of the DNR.
- 2. The Provider must immediately document the communication, indicating whom the communication was with, who witnessed the communication and the date and time of the communication. The Provider must ask the parent/legal guardian to sign a written acknowledgment of this communication.
- 3. The communication must be witnessed by someone other than the parent, who must confirm that the communication took place.
- 4. Communications referenced above are not required if the Provider unsuccessfully makes a reasonably diligent and documented effort to contact the parents or legal guardian for at least 48 hours. If following that period, a DNR order is written, the Provider will document the reason for the order.
- 5. A Provider is not required to initially provide or continue resuscitative measures on the minor if the resuscitative measures would be medically inappropriate because providing treatment would, in the Provider's reasonable medical judgment, either
  - create a greater risk of causing or hastening death or be potentially harmful, or
  - cause unnecessary pain, suffering or injury to the minor because there is no further benefit in performing resuscitative measures.
- 6. If the parent requests transfer of a minor, the parent will be given 24-48 hours to find another Provider willing to accept the minor before the DNR is implemented. If an accepting Provider is found, reasonable efforts will be made to transfer the minor.
- 7. Upon request, this policy will be provided to the minor or his/her parent.

Decisions contrary to Provider judgment or personal ethics	1. The Ethics Committee/Clinical Ethicist may be consulted by the Provider, patient, healthcare staff, or Surrogate when conflict is unresolved. If no resolution is possible, the patient/Surrogate should be offered the opportunity to locate another Provider who may be willing to provide requested treatments.
	While the bosnital and Provider may provide assistance, the

- While the hospital and Provider may provide assistance, the patient/Surrogate is ultimately responsible for finding another accepting Provider.
- If no accepting Provider is available, the Chief Medical Officer, Hospital Administration and/or Risk Management must be contacted.
- 2. If a patient with DMC, his/her Surrogate Decision-Maker, or his/her Health Care directive directs the withdrawal/withholding of LST and the Provider, because of reasons of conscience, objects to a request for withdrawal/withholding of LST, the Provider shall assist with the transfer of the patient to a Provider who will effectuate the directive.
- 3. Although patients/Surrogates have the right to refuse medical treatments, they do not have the right to compel clinicians to order treatments the clinician considers medically inappropriate.
  - In addition, Providers need not provide new or augmented treatment or restart treatment that had previously been discontinued when requested by a patient or Surrogate Decision-Maker where, in such provider's judgment, such treatment is not medically indicated, is without benefit, or is harmful. Such treatments include, but are not limited to,
    - o additional or higher doses of medications,
    - o administration of blood products,
    - $\circ$  resuscitative measures, such as CPR and cardioversion and
    - o diagnostic testing and/or imaging
- 4. Where a patient/Surrogate requests Full Code status and the Provider believes such treatment is not appropriate, the Provider should reinforce the advantages of a non-full code status. If there is continued disagreement between the Provider and the patient/Surrogate, another Provider, a Palliative Care Provider, where available, or the Ethics Committee/Clinical Ethicist may be consulted for assessment and further communication with the patient/Surrogate.
  - If the Palliative Care Provider or Ethics Committee/Clinical Ethicist agrees that Full Code status is not appropriate:
    - The patient/Surrogate must be advised that the Provider intends to write a DNR/DNI order.

Decisions contrary to Provider judgment or personal ethics, continued	<ul> <li>If the patient/Surrogate disagrees, they will be provided an opportunity to find a new accepting Provider and transfer care.</li> <li>In the absence of a court order, a DNR/DNI order may be written with either:</li> <li>Documented agreement of the Ethics Committee/Clinical Ethicist or</li> <li>Documented concurrence of a second Provider</li> </ul>
	<ol> <li>Where the decision has been made not to order new or augmented treatment and, in the Provider's judgment, continuation of current treatments, including but not limited to mechanical ventilation, vasopressors and dialysis, are not medically indicated, without benefit, or harmful, the following are recommended:</li> </ol>
	<ul> <li>The patient/Surrogate must be advised that the Provider intends to discontinue ordering the treatments.</li> <li>If the patient/Surrogate disagrees, a Palliative Care Provider, where available, should be consulted for assessment and further communication with the patient/Surrogate. If the Palliative Care Provider agrees with the Provider and there is continued disagreement, the Ethics Committee/Clinical Ethicist should be consulted. In the absence of a Palliative Care Provider, the Ethics Committee/Clinical Ethicist should be consulted. In the absence of a Palliative Care Provider, the Ethics Committee/Clinical Ethicist should be consulted. If the Ethics Committee/Clinical Ethicist agrees that the care requested is not appropriate, the patient/Surrogate should be provided an opportunity to find a new accepting Provider and transfer care within 24 hours.</li> <li>If no accepting Provider or facility is found, treatment may be stopped. CMO should be apprised of such situations.</li> </ul>
Method of foregoing life- sustaining procedures	<ol> <li>Withdrawal of ventilator support is performed by the Provider or by nursing staff or respiratory therapy staff if the patient or the Surrogate and family have consented to the withdrawal and the Provider has ordered the withdrawal.</li> </ol>
	2. Artificial, Nutrition, and Hydration (ANH)
	<ul> <li>In Arizona, California, Nebraska, Nevada, and Wyoming:</li> </ul>
	<ul> <li>The decision to withhold (not initiate) ANH may be made by the patient or Surrogate Decision Maker.</li> <li>The decision to withdraw (discontinue) ANH may only be made with the</li> </ul>

o The decision to withdraw (discontinue) ANH may only be made with the consent of the patient with capacity or, if the patient lacks capacity, with a specific Advance Directive or by a Health Care Power of Attorney or Guardian appointed by a court to make healthcare decisions with express authority to withhold or withdraw LST.

Method of foregoing life- sustaining procedures, continued	<ul> <li>In <u>Arizona</u> where ANH are commenced, a Health Care Power of Attorney or Guardian may decide to withdraw ANH; a Surrogate decision maker may not authorize the withdrawal of ANH.</li> <li>In <u>Colorado</u>, the decision to <b>withhold</b> or <b>withdraw</b> ANH may be made by the patient or Surrogate Decision Maker unless the Surrogate Decision-Maker is appointed by proxy, in which case a second independent Provider (neurologist or neurosurgeon) must document that the ANH will prolong the act of dying.</li> <li>Notwithstanding, a Provider may withdraw food or fluid where the provision of</li> </ul>
-	food or fluid is not medically possible, where the provision of food or fluid would hasten death or where, because of the patient's medical condition, the patient is incapable of digesting or absorbing the food or fluid.
Newborns	<ol> <li>The primary consideration for decisions regarding LST for seriously ill newborns should be what is best for the newborn. Factors that should be weighed are as follows:</li> </ol>
	<ul> <li>The chance that the therapy will succeed.</li> <li>The risk involved with treatment and non-treatment.</li> <li>The degree to which the therapy, if successful, will extend life.</li> <li>The pain and discomfort associated with the therapy.</li> <li>The anticipated quality of life for the newborn with and without treatment.</li> </ul>
	2. In Arizona, parents of an infant may only refuse to consent to medical treatment or surgical care that is not necessary, including care or treatment that:
	<ul> <li>Is not necessary to save the life of the infant;</li> <li>Has a potential risk to the infant's life or health that outweighs the potential benefit of treatment;</li> <li>Is futile treatment or treatment that will do no more than temporarily prolong the act of dying.</li> </ul>
	3. A DNR order may not be implemented for a newborn not under juvenile court jurisdiction before the Provider has communicated with at least one of the newborn's parents/legal guardian.
	<ul> <li>The newborn's care plan, including implementing a DNR order and what the order means;</li> <li>The parent's right to request that the newborn be transferred to another facility; and</li> <li>The parent's right to seek a court order blocking the implementation of the DNR.</li> </ul>

End-of-Life care when death is imminent	1.	When the decision is made to withdraw LST and death is expected to occur shortly thereafter, the focus changes from the management of disease process to the patient's comfort and symptom management. The family also must be supported during this period. The patient's comfort includes physical, emotional and spiritual comfort. If the patient has directly expressed specific desires for the end of his/her life or expressed his/her desires through family members, these desires should be honored if at all possible and if determined by the Provider to be appropriate.
	2.	A DNR/DNI order should be entered into the medical record and medication should be provided in sufficient amounts to relieve pain, anxiety, dyspnea, and other symptoms.
	3.	If the patient and family wish that the patient be transferred to the patient home or to a hospice service, such request should be honored whenever possible. If this cannot be accomplished, care in the facility is directed toward removal of unnecessary diagnostic measures, medications, treatments and even vital sign checks that do not add to comfort. Visitor restrictions should be relaxed so the patient can have family present to support the patient and other family members.
	4.	Once a patient is declared brain dead, artificial maintenance of cardiac, pulmonary function and other vital organs may be continued for a reasonable period of time at the request of the family/Surrogate.
	5.	Bereavement care should be available for the family members after the patient dies.
Review of order	to t	order for withholding/withdrawal of LST shall be periodically reviewed in relation the patient's clinical condition. Review and documentation occurs whenever there a substantial change in the patient's status.
Rescission of order	1.	An order for withholding/withdrawal of LST shall be rescinded upon the request of the patient with capacity or the Surrogate Decision Maker unless two Providers have determined that resuscitation is not medically indicated, is without benefit or would be harmful. If conflict arises between the Health Care Directive and the legally authorized representative, contact Risk Management.
	2.	In Colorado, only the patient or Surrogate Decision Maker who gave the orders for withholding/withdrawing LST may revoke those orders.
		Continued on next page

Brain death / organ donation	<ol> <li>If withdrawal/withholding LST is being considered, the appropriate OPO should be notified first.</li> </ol>
	2. After declaration of brain death, LST may be withdrawn/withheld without consent if the patient is not an organ donor. Cardio-pulmonary procedures should only be withheld/withdrawn from the patient in consultation with the OPO.
Conflict resolution	<ol> <li>Conflict resolution should be sought whenever patient, family members, or care givers disagree on the provision of care and/or the withdrawal/withholding of life support. See also section above: Decisions contrary to Provider judgment or personal ethics.</li> </ol>
	2. A consultation with the Ethics Committee/Clinical Ethicist may be sought as needed. The purpose of such consultation is to assist the involved parties in making difficult decisions. In general, the Ethics Committee/Clinical Ethicist will clarify the ethical issues involved in caring for the gravely ill patient. There may be instances where the Ethics Committee/Clinical Ethicist, upon review of clinical data and opinions, will be asked whether care is appropriate. Where the committee lacks the clinical expertise, it may consult with medical staff members and others as necessary.
Documentation	<ol> <li>An order for DNR/DNI or withdrawing/withholding of LST must be documented in the Provider's orders. The supporting basis for the order as well as the specifics of all relevant conversations must be included in the medical record. Opinions of consulting Providers must also be documented in the medical record.</li> </ol>
	<ol> <li>Telephone orders for DNR/DNI and/or withdrawing/withholding LST are discouraged but are acceptable when witnessed by two RNs who listen to the order on the phone at the same time. All such orders must be co-signed by the responsible Provider within 24 hours.</li> </ol>
	<ol><li>A Pre-hospital Health Care Directive may serve as a DNR/DNI order in the outpatient setting and in the Emergency Room.</li></ol>
	<ol> <li>The responsible Provider should document whether he/she obtained an Ethics Committee/Clinical Ethicist consultation, and if so, the direction, if any, provided by the Ethics Committee/Clinical Ethicist.</li> </ol>
Pediatrics / Newborns	<ol> <li>End of life decisions will be discussed in a care conference with the patient's decision maker and family and with the knowledge of all Providers contributing to the care of the patient.</li> </ol>
	Continued on next page

Pediatrics / Newborns, (continued)

- Scheduling of the care conference will be done as soon as practical after the Provider(s) or family/guardians indicate that end of life decisions are necessary.
  - A designated staff member will set a time and place for the conference, taking into consideration the family decision maker/family schedule and needs and whenever possible the schedule of the individual Providers and members of the interdisciplinary team.
  - Providers who wish to have input into the decision making will make every effort to attend or will communicate their input to a member of the team who is attending.
- 3. The end of life decisions made at the care conference will be documented in the electronic medical record by the Provider.
  - Providers unable to attend the meeting will be responsible for reviewing the summary of the conference prior to speaking with family members.
- 4. Each patient will be assessed for actual or anticipated symptoms such as pain, dyspnea associated respiratory distress, and terminal restlessness. Symptoms will be treated with appropriate and adequate administration of medications including opioids and sedatives.
- 5. Whenever possible, distressing symptoms such as excessive broncho-pulmonary secretions and post-extubation stridor will be prevented by means of timely withdrawal of the administration of parenteral fluids, pharmacological treatment of iatrogenic over-hydration, and administration of medications including methylprednisolone and anticholinergic agents.

## **Procedures and Documentation**

Providing and<br/>documenting<br/>careInformation on providing and documenting care may be found in the Lippincott<br/>Procedures: Withholding and Withdrawing Life-Sustaining Treatments<br/>care

## **Other Information**

AdditionalInformation on the cultural aspects of withdrawal of care may be taken into<br/>consideration.

# Other Information, Continued

Additional	Arizona Revised Statutes §36-418
information	Arizona Revised Statutes §36-2281
	Arizona Revised Statutes § 36-418. "Simon's Law", H.R. 2122, 1 <sup>st</sup> Sess. (2019)
	AAHPM. (2013). Hospice/palliative care training for Providers.
	American Academy of Hospice and Palliative Medicine Alleviating Psychological and
	Spiritual Pain in the Terminally III.
	American Academy of Pediatrics and American Heart Association, (2016), Neonatal
	resuscitation textbook (7th Ed.). Elk Grove Village, IL: American Academy of
	Pediatrics.
	American Academy of Pediatrics Clinical Report: Withholding Medically
	Administered Nutrition in Children. July 27, 2009
	American Academy of Pediatrics Committee on Bioethics. (2009 and reaffirmed
	January 2014). Clinical report - forgoing medically provided nutrition and
	hydration in children. <i>Pediatrics,</i> 124(2), 813-822.
	American Medical Association's Council on Ethical and Judicial Affairs. Decisions
	near the end of life.
	Appelbaum, P. (2007, November). Assessment of patients' competence to consent
	to treatment. New England Journal of Medicine, 357. 1834-1840.
	Carter, Brain MD, Levertown, Marci and Friebert, Sarah. (2011). Palliative Care for
	Infants, Children and Adolescents – A Practical Handbook (2 <sup>nd</sup> Ed). Johns
	Hopkins University Press
	Center to Advance Palliative Care <u>https://www.capc.org/</u>
	Emancipation Law and Legal Definition, US Legal Definitions,
	www.definitions.uslegal.com End of Life Nursing Education Consortium– Pediatric Palliative Care (ELNEC-PPC)
	Training Program (2014). City of Hope, American Association of College of
	Nursing.
	Ferrell, B. & Coyle, N. () <i>Textbook of Palliative Nursing, 2<sup>nd</sup> edition</i> . Oxford University
	Press.
	Goldman, Ann, Hain, Richard, and Liben Stephen. (2012). Oxford Textbook of
	Palliative Care for Children (2 <sup>nd</sup> Ed). Oxford University Press
	Hospice Net (n.d.). The hospice concept. Accessed 2/23/2010 at
	http://www.hospicenet.org/
	International Association for Hospice and Palliative Care (2009). Pallipedia: The
	IAHPC palliative care online dictionary. Accessed 2/23/2010 at
	http://www.hospicecare.com/
	Kuebler, K., Heidrich, D., & Esper, P. (). Palliative and end of life care clinical
	practice guidelines, 2 <sup>nd</sup> edition. St. Louis: Saunders.
	Lacey, M. and Callister, L. (2010). Parent Involvement in End of Life Care and
	Decision Making in the Newborn Intensive Care Unit: An integrative Review.
	J Perinat Educ, winter, 19(1):29-39.
	Lurie. R. () Deciding for the patient without decision-making capacity: Legal devices.
	Comprehensive Cancer Center of Northwestern University
	Maradiegue, A. (). Minor's rights versus parental rights: Review of legal issues:
	Exemptions from parental consent for minors. Fairfax, VA: George Mason
	University.

# Other Information, Continued

Additional information, (continued)	<ul> <li>Multi-Society Task Force (1994, May). Multi-Society task force on persistent vegetative state. <i>New England Journal of Medicine, 330</i>. 1499-1508.</li> <li>National Association of Neonatal Nurses. (May, 2016). Position Statement #3067: NICU Nurse Involvement in Ethical Decisions (Treatment of Critically III Newborns). Retrieved from <a href="http://nann.org/about/position-statements">http://nann.org/about/position-statements</a></li> <li>National Association of Neonatal Nurses. (February, 2015). Position Statement #3063: Palliative and End-of Life Care for Newborns and Infants. Retrieved from <a href="http://nann.org/about/position-statements">http://nann.org/about/position-statements</a></li> <li>Solomon, M. Z., Sellers, D. E., Heller, K. S., Dokken, D. L., Levetown, M., Rushton, C., Truog, R. D., &amp; Fleischman, A. R. (2005). New and lingering controversies in pediatric end-of-life care. <i>Pediatrics</i>, 116, 871-883.</li> <li>Wolfe, Joanne. Hinds, Pamela, and Sourkes, Barbara. (2011). Textbook of Interdisciplinary Pediatric Palliative Care. Saunders</li> </ul>		
Other related policies	<ul> <li>NOTE: Unless specified as a System policy, policies are applicable only to the identified facility/region.</li> <li>Applicable Regional or Facility Specific Policies for <i>Advance Directives</i> <ul> <li>Advance Health Care Directives for Nebraska</li> <li>Advance Health Care Directives of Nevada</li> <li>Advance Health Care Directives of Wyoming</li> <li>Advance Health Care Directives of Wyoming</li> <li>Arizona Advance Health Care Directives</li> <li>BLMC Advance Health Care Directives</li> <li>Colorado Advance Health Care Directives</li> </ul> </li> <li>BGMC, BMDACC, BTMC: Electroneurodiagnostics - Cerebral Death Determination</li> <li>System: Consent Policy</li> <li>System: Anatomic Organ Donations: Organ, Tissue, and Eye Procurement</li> <li>System: Qualified Interpreters</li> <li>System: Qualified Interpreters</li> <li>System: Surrogate Decision Makers</li> </ul>		
Keywords	<ul> <li>Allow Natural Death</li> <li>AND</li> <li>DNAR</li> <li>DNR</li> <li>Do Not Resuscitate</li> <li>Do Not Attempt to Resuscitate</li> <li>End of Life</li> <li>End of Life</li></ul>		
Appendix	Pediatric Guidelines for Patient Family Conference and Care Conference		

## **Pediatric Guidelines for Patient/Family Conference and Care** Conference

Definitions Family Conference: formal or informal meeting with patient, family and health care team to facilitate communication regarding the diagnosis, prognosis, plan of care, transition or discharge plan, patient family goals and resources. Most family conferences will be held to prevent or address communication issues and to resolve identified or anticipated concerns.

> Care Team Conference: formal or informal meeting of health care team involved in the care of a patient to communicate and or develop the plan of care. The patient and family are not present.

Conference

Indicators for Family Conference and/or Care Conference:

indicators

Family Conference (may also need Care Conference)	Care Team Conference Only
New diagnosis of a chronic or life threating disease Change in patient status or change in goals of care	
Multiple specialties and need for coordination	Need for coordination among multiple specialties
long length of stay: Gen peds 7-10 days PHO 7-10 days PICU 3-7 days	Health care team disagreement No primary (or consistent) assignment of RN to patient
Health care Provider/family miscommunication or conflict	No clear Provider leader
Family wanting everything done for the patient including futile or minimally beneficial treatments	
Differing messages from family members	Team member request not to care for patient
Boundary conflicts	Patient and/or family perceived as "challenging"
Family conflict or mistrust of caregivers	Acute or chronic mental health condition complicating plan of care
Uninvolved family	
Alternative sites of care are indicated	
Health care team needs information about the patient/family cultural and spiritual beliefs	
Debriefing after a significant event or death	

# Pediatric Guidelines for Patient/Family Conference and Care Conference, Continued

How to request	Any staff member may request a family conference or care conference (typically occurs during daily interdisciplinary team rounds). Social worker, case manager or care coordinator is responsible for organizing the conference and inviting the team members.
Who attends	Patient/family, others the patient/family wishes to invite, attending and consulting Providers, care coordinator, primary RN, case management, social worker, and other team members involved in the care whose expertise is needed (chaplain, physical therapist, child life specialist, occupational therapist, speech therapist, pain team, pharmacist, home care team, clinical nurse specialist).
Before the meeting	<b>Health Care team</b> : some members of the team may need to meet prior to family conference to clarify your goals for the conference (what decisions are you hoping to achieve), review the chart to ensure knowledge of all medical issues (history, prognosis, treatment options, family psychosocial information, legal guardians), coordinate medical opinions among consultant Providers and determine a Provider to present medical information from all services to patient/family, decide what tests/treatments are medically appropriate (likely to benefit the patient), make sure that the right people are included in the meeting, identify a facilitator (usually not the Provider), resolve or identify team conflicts around plan of care (if conflict is involved then all parties need to be at the team conference), come to consensus with plan of care.
Facilitator's role	May be from any of the disciplines. Tasks include: facilitate introductions, explain purpose and goals of conference, review ground rules, ask family to identify their questions, concerns and goals, invite review of medical status, facilitate discussion among those present, clarify understanding (especially medical of terminology), summarize discussion, identify follow-up, and document Patient/Family Care Conference in medical record.

# Pediatric Guidelines for Patient/Family Conference and Care Conference, Continued

### Conference format

1.	Establish setting. Private, comfortable,	
	everyone seated, turn off pager/cell phone	
2.	Introductions Allow everyone to state	Can you tell me something about your child? What kind
	name and relationship to patient. Build	of person is he/she?
	relationship: ask non-medical question	
	about the patient.	
3.	•	
	respectful discussion. Discuss purpose	
	of and need for patient/family conference.	
	Identify goals and desired outcome of	
	family conference.	
4.	Assess Patient/Family Understanding.	Tell me in your own words what your understanding is
	Identify family needs and wishes.	of your son/daughter's condition at this time?
	Encourage all present to respond. Ask for	
	descriptive of changes in function over	
	course of illness/hospitalization.	
5.	Medical Review/Summary	I'm afraid I have some bad news or I'm sorry to have to
	Summarize the diagnosis "big picture" in a	tell you this - your son/daughter has xxx.
	few sentences.	
6.	Silence/Reactions – if delivering bad	"This must be very hard"
	news allow family to respond, anticipate	"I can only imagine how scary/difficult/overwhelming this
	emotional reactions, have tissues	must be"
	available, and prepare for common	"You appear angry, can you tell me what is upsetting
	reactions (acceptance, conflict, denial,	you?"
_	grief, despair). Respond empathically.	
7.		"Some people like to know every detail about their
	implications of illness and Treatment	child's illness, others prefer a more general outline.
	<b>Options</b> . Assess how much the patient	What kind of person are you?"
	and family want to know. Make a	
	recommendation based on knowledge and	
0	experience.	Mbatara you baning for? Mbatia most important for
о.	Assess patent and family goals.	What are you hoping for? What is most important for
	Identify current and anticipated	you at this time? How will this decision affect you and
	stressors. Identify resources among	other family members?
	patient, family, staff, and community that	
	can support patient and family coping. Explore and identify hopes and goals	
	beyond elimination of current issues.	

# Pediatric Guidelines for Patient/Family Conference and Care Conference, Continued

#### Conference format, (continued)

9. Translate goals into care plan. Review current & planned interventions. If appropriate make recommendations to continue or stop based on goals. Allow family time to make necessary decisions. If appropriate discuss DNR/AND, home care. Summarize the decisions made.	"Given what I know about this illness and what you have told me about your child, I would recommend xxx". These decisions are very hard. What do you think your child would want (if appropriate)? You have told me your goals are with this in mind, I do not recommend the use of artificial or heroic means to prolong the dying process. If you agree with this, I will write an order in the chart that we will not resuscitate. We will do everything possible to make your child comfortable.
<ol> <li>Identify follow-up. Need for additional meeting. Confirm your continued availability.</li> </ol>	We've talked about a lot. Do you have any other questions or concerns? I want to give you some time to think about your options. We will need a decision by xxx. I want you to know that I'm available if you have any questions. You can ask the nurse to page me. We'll plan to meet again in a week to review where we are."
11. <b>Document.</b> Who was present, what was discussed prognosis and treatment options and if any decisions were made, follow-up plan.	<b>Team debriefing = Opportunity for teaching and</b> <b>reflection</b> . Ask team members: How do you think the meeting went? What went well? What could have gone more smoothly? What will you do differently in the future?

# Managing conflict

- Listen and make emphatic statements.
- Determine source of conflict: guilt, grief, culture, family, dysfunction, trust in health care team, etc.
- Clarify misconceptions
- Explore values behind decisions
- Set time-limited goals with specific benchmarks (e.g. improved cognition, oxygenation, mobility)