Considerations Regarding Life-Prolonging Treatment Decisions for Residents of Long-Term Care Facilities

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Members of the Missouri Long-Term Care Task Force convened by the Center for Practical Bioethics (formerly, Midwest Bioethics Center) developed the following policy guidelines out of growing concern about the issues surrounding life-prolonging treatment decisions for residents of long-term care facilities.

Recent judicial and legislative actions (i.e., Cruzan, Patient Self-Determination Act) underscore the importance of policies that support resident-focused decision making in long-term care facilities. However, both ethical and legal uncertainty surrounding residents’ rights to accept or to refuse life-prolonging treatments has led to confusion among long-term care facilities regarding policy development and appropriate action. Compounding providers’ confusion about residents’ legal and ethical rights is the uncertainty about regulatory sanctions. To address these problems, this document is intended to provide guidance to long-term care facilities for policy development in several key areas related to life-prolonging treatment decisions, including

- Residents’ rights;
- Advance directives;
- Surrogate decision making;
- Documentation of decisions;
- Conflict resolution;
- Care of residents who are dying;
- Hospice care.

These guidelines represent the views of this Task Force. They have been reviewed and discussed by the Missouri Division of Aging Ethics in Long-Term Care Task Force. There is general concurrence with the content of these guidelines.

1. Purpose/Rationale/Goals

1.1 Provide practical guidance to long-term care facilities developing policies and procedures about decisions regarding life-prolonging treatment and advance directives.

1.2 Provide guidance about decision making for persons who lack decisional capacity and have not made advance directives.

1.3 Offer guidelines for decision making based on systematic, rational considerations that respect the dignity and autonomy of long-term care residents.

1.4 Establish a coherent philosophical/ethical foundation for decision making about life-prolonging treatment and advance directives.

1.5 Provide support to individuals who are faced with making life-prolonging treatment decisions — especially decisions about withholding or withdrawing artificial nutrition and hydration.

2. Problems/Needs to be Addressed

2.1 The traditional decision-making role of physicians and families/surrogates for persons without decisional capacity is unclear.

2.2 Because of legal concerns, providers and families/surrogates are reluctant to make healthcare decisions for persons without decisional capacity.
2.3 Policies and procedures regarding the use of life-prolonging treatment and advance directives are needed and should be developed by long-term care facilities.

2.4 People involved in the decisions of long-term care residents need education and guidance.

3. Definitions

3.1 Advance directives — this term may refer to any direction either written or oral that a person makes about his or her healthcare wishes prior to losing decisional capacity. Written advance directives may include living wills, healthcare treatment directives, and durable powers of attorney for healthcare. (For more explanation of oral directives, see section 9.)

3.2 Clinically appropriate — a treatment decision that is consistent with both prevailing medical standards of clinical practice and sound ethical decision-making criteria (see 8.4.b.i-iii).

3.3 Comfort care — a range of treatments intended to provide relief of pain and/or suffering, control symptoms, reduce anxiety, and provide comprehensive support to residents.

3.4 Decisional capacity — term used to reflect the ability of a resident to make a specific decision, for example, the ability to understand relevant information, to reflect on it, and to communicate (verbally or nonverbally) to providers.

3.5 Do not resuscitate (DNR) — a physician’s order protecting a resident from cardio-pulmonary resuscitation where resuscitation has been determined either to be futile or to be inconsistent with the resident’s values, wishes, and goals.

3.6 Durable power of attorney for healthcare decisions — a legal document that allows a person to name an agent to make healthcare decisions.

3.7 Ethics committee — a multidisciplinary committee convened to integrate ethics into a healthcare providing institution/facility. Ethics committees serve three functions: education, policy review and development, and case consultation. They are an advisory resource; they do not make treatment decisions.

3.8 Family — a relative or intimate friend of the resident.

3.9 Futile — a treatment may be determined to be futile if the attending physician believes there is no reasonable expectation that the treatment will achieve its intended goal.

3.10 Hospice — a treatment approach for persons who are terminally ill involving the skilled and compassionate care of dying patients and their families. The goals of hospice include maximizing control by the resident, keeping the resident pain free, and comfortable during the final phases of life.

3.11 Informed consent — agreement by a resident with decisional capacity made voluntarily and without coercion upon a clear understanding of (1) the nature of the resident’s medical condition and prognosis, (2) the nature and purpose of the proposed treatment or procedure, and (3) the benefits and burdens of proposed treatment alternatives or nontreatment.

3.12 Life-prolonging treatment — interventions that are judged likely to be effective in prolonging the life of a resident or which are used simply to maintain bodily function.

3.13 Living will — a document stating a person’s wishes with regard to the use of life-sustaining (or death-prolonging)
treatment in the event that the person has a terminal condition and is unable to communicate. Most states, including Missouri, have statutorily suggested forms. Use of the statutory form is not required. The term living will is also often used in a generic sense to refer to any document stating a person’s healthcare treatment wishes.

3.14 Provider — professionals and agents of the facility, authorized by law to provide healthcare.

3.15 Surrogate — an agent who acts on behalf of a resident who lacks decisional capacity to participate in a particular decision; an appropriate surrogate may be:

a. designated by the resident (e.g., in a healthcare treatment directive, living will, or durable power of attorney);

b. the adult who is most involved with the resident and most knowledgeable about the resident’s personal values and preferences; or

c. designated by a court (e.g., a guardian).

No priority is intended in this listing.

3.16 Terminal condition — a condition or illness, usually thought of as irreversible, unrelenting, and without cure, which because of its nature can be expected to cause the resident to die.

4. Identification of Ethical Principles/Values

Healthcare has traditionally been based in large part on the assumption that human life is precious and that it should be preserved whenever possible. This principle is fundamental to the healthcare enterprise. However, taken as an absolute it negates other valuable ethical principles and does not provide a full understanding of the principles that should be considered when making decisions regarding withholding/withdrawing treatment.

The ethical imperative for healthcare providers is to care. Caring implies balancing all essential ethical principles.

4.1 The principle of autonomy.

Residents have the right to make decisions about the course of their lives; this is often called the right of self-determination.

4.2 The principle of beneficence.

Long-term care providers have an obligation to avoid harming and to promote the well being of their residents.

4.3 The principle of justice/equity.

All persons have a duty to respect the rights of others, to obey morally acceptable laws, and to distribute limited resources fairly.

5. Working Assumptions

5.1 When a resident has refused life-prolonging treatment or when it is clinically appropriate to withdraw such treatment, healthcare providers have an obligation to offer treatment and care that provides for a peaceful and dignified death with minimal suffering.

5.2 If doubt exists regarding the wishes of the resident/surrogate about possible benefits or burdens of a treatment when treatment wishes are not clear, providers should initiate time-limited trials for a reasonable period.

5.3 When a decision to forgo a particular life-prolonging treatment is made, both healthcare providers and the facility have a continuing obligation to provide a comprehensive range of comfort care and supportive treatment. The care of dying
persons may be facilitated through a hospice approach.

5.4 Healthcare providers are obligated to respect reasonable requests of residents/surrogates to provide or to continue life-prolonging treatments.

5.5 DNR (Do Not Resuscitate) is a medical order that should be signed by the resident’s primary physician. Orders not to resuscitate should be discussed with residents who have decisional capacity or with their surrogates if they do not have decisional capacity.

5.6 Healthcare providers should respect the request of residents/surrogates for consultation and opinions from additional experts.

6. A Summary of Relevant Law and Other Legal Tenets

6.1 Constitutional law: in the Cruzan case, the U.S. Supreme Court acknowledged a constitutional basis for a competent person’s right to refuse medical treatment, including artificial feeding, defined as a right of “liberty” from unwanted medical treatment.

6.2 Federal Legislation: The Patient Self-Determination Act, passed by the U.S. Congress in 1991, requires nursing homes to inform their clients at the time of admission of their right to make healthcare treatment decisions with advance directives. Under this legislation nursing homes are required to

a. maintain written policies and procedures concerning a person’s rights under state law (whether statutory or recognized by the courts), to make decisions concerning their care including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives;

b. ensure that this written information is provided to adult residents/surrogates at the time of admission;

c. note in the resident’s records whether an advance directive has been made by the resident;

d. ensure compliance with advance directives consistent with state law;

e. provide staff and community education on advance directives; and

f. assure residents that they are not required to complete advance directives.

6.3 Missouri Statutes

a. The Missouri Life Support Declarations Act (RSMo Chapter 459.010-459.055) grants competent individuals the right to sign an advance declaration (“statutory living will”) for withholding or withdrawing “death prolonging procedures.” However, a statutory living will may not direct the withholding/withdrawing of food or water. Use of the statutory form is not required. Living wills, which are not in the statutory form, are sometimes referred to as “common law living wills.”

b. A statutory living will becomes effective only when a declarant’s medical condition is determined to be terminal and when he or she has lost decisional capacity. Terminal condition is defined in the statute as “an incurable or irreversible condition which, in the opinion of the attending physician, is such that death will occur within a short time regardless of the application of medical procedures.”

c. Missouri’s Durable Power of Attorney for Healthcare Law (RSMo Chapter 404.800-.865; effective August 1991)
allows competent individuals to designate a “surrogate” or “attorney-in-fact” to make healthcare decisions for them in the event that they lack decisional capacity as determined by two physicians unless the durable power of attorney allows decisions as to incapacity to be made by one physician.

A surrogate must consider the individual’s medical diagnosis, prognosis, and the benefit and burdens of proposed treatment as well as the individual’s comfort care. The authority of a surrogate to withhold/withdraw artificial food or water must be specifically provided for in the document.


a. Cruzan

a.i To be assured of legal protection, there must be clear and convincing evidence that the resident would request that artificial nutrition and hydration be withheld or withdrawn.

a.ii In addition to specific written advance directives, clear and convincing evidence may also be established by verbal statements that reflect what treatment choices a resident would make.

b. Warren

b.i Guardians are authorized by statute to make healthcare treatment decisions (both to give and withhold consent) to further their wards’ best interests without specific court authorization. Factors that may influence a determination of best interests include medical diagnosis and prognosis, benefits and burdens of treatment, preferences expressed by the ward, and the probability that a course of action will lead to recovery or relief of pain.

b.ii Court appointed guardians have statutory authority to make healthcare decisions in their wards’ best interests without specific court authorization.

b.iii. The clear and convincing evidence requirement in the Cruzan case should be limited to situations involving the withdrawal or withholding of artificial nutrition and hydration and should not control other life-sustaining care decisions.

The concurring opinion in Warren emphasizes that a court appointed guardian’s authority to withhold consent to care pertains to treatment that is unnecessary or harmful, and that the power to consent to DNR orders without court approval is not unlimited. That is, the power is only to be exercised when a sufficient medical basis is established without regard to the patient’s handicap, the social utility of the patient’s life, or the value of that life to others.

6.5 Other Legal Tenets

a. A resident’s decision to forgo life-prolonging treatment does not constitute a decision to commit suicide.

b. Requests by a resident for interventions intended to terminate his or her life should not be honored.
c. Healthcare providers and/or facilities that have an objection to a decision to forgo treatment should inform the resident or surrogate of the objection and assist in the orderly transfer of care to another provider or facility.

d. Any medical or surgical intervention may be withheld or withdrawn under appropriate circumstances.

e. If a facility changes its policy or procedures regarding the use of life-prolonging treatment, the facility has an obligation to inform its residents/surrogates of those changes and has a duty to help the residents transfer to another facility if they desire.

7. A Summary of Missouri Division of Aging Regulations

7.1 A nursing facility is required to respect the rights of its residents. Those rights include

a. The right to be informed by a physician of their medical condition and prognosis (19 CSR 30-88.010[10]).

b. The right to be afforded the opportunity to participate in the planning of their care and the right to refuse treatment (19 CSR 30-88.010[11]).

c. The right to be transferred or discharged only for medical reasons, or for their health or welfare or that of other residents or for nonpayment of stay (19 CSR 30-88.010[14]).

7.2 The operator and administrator of a nursing facility have a responsibility to provide protective oversight to the residents of that facility and to assure that they receive appropriate nursing and medical care (19 CSR 30-85.042[3] & [67]).

7.3 A nursing facility is required to develop policies and procedures for dealing with medical emergency treatment procedures, admission and discharge procedures, and resident rights' issues. (19 CSR 30-85.042[13]). The facility's staff, all physicians with residents in the facility, and each resident must be informed of those policies and procedures. Facilities are required to relate information about advance directives to residents/surrogates on an annual basis (19 CSR 30-85.042[15] & [42] and also 19 CSR 30-88.010 [9]).

7.4 A nursing facility is required to meet the nutritional needs of a resident based on the individual's circumstances, medical condition, and goals of treatment as determined and justified by the physician (19 CSR 30-85.052 [1]).

8. General Guidelines for Decision Making

8.1 Model of Decision-Making Process

a. Long-term care residents have the right to accept or refuse any health care treatment.

b. Informed decisions must include participation by providers and residents/surrogates.

c. Treatment decisions may be changed at any time if it is appropriate in view of a reassessment or change in the condition of the resident. The resident/surrogate should be involved in the decision.

8.2 Role of the Resident

a. Residents with decisional capacity: Adults with decisional capacity have the right to accept or refuse any medical intervention. These rights are not
restricted to residents who are terminally ill.

Residents who have been adjudicated incompetent or diagnosed as having a mental illness or mental retardation may have the ability to make some, if not all, healthcare treatment decisions.

b. Residents who have advance directives: If a resident who has an advance directive stating his or her treatment preferences is currently without decisional capacity, his or her directive should be followed.

c. Residents without decisional capacity and without advance directives: When possible, appropriate surrogates should be identified to act on the resident’s behalf.

The legal authority of surrogates who have not been formally appointed by an advance directive or a court order may be open to challenge.

c.i An appropriate surrogate is one who has personal knowledge of the resident and is willing to act on behalf of the resident.

c.ii In many instances a family member will be an appropriate surrogate, but even when there is family, close friends or others may be better suited for this role.

c.iii An adult who has lived with the resident prior to the resident being admitted to a long-term care facility may be given priority as a surrogate decision maker. For example, a person living with his or her spouse (or partner) may speak for his or her spouse (or partner).

c.iv Each facility should establish policies and procedures describing their internal process for recognizing an appropriate surrogate. Ethics committees may be helpful in this process.

c.v Requesting a court appointed guardian should be an option of last resort.

8.3 Role of Surrogate Decision Makers for Residents without Decisional Capacity

a. Appropriate surrogates should participate in decision making for persons who lack decisional capacity.

b. Surrogates named in durable powers of attorney for healthcare decisions:

b.i Generally, surrogates have the same authority as the resident would have if he or she had decisional capacity.

b.ii Missouri law requires that a surrogate’s authority to withhold or withdraw artificially administered nutrition and hydration be expressly provided.

c. Surrogates named in durable powers of attorney signed before August 1991:

b.i May or may not have legal authority to make healthcare decisions unless the durable power of attorney specifically contains that authority.

b.ii Prior to August 1991, many people who are now long-term care residents signed durable power of attorney documents which did not specifically mention healthcare decision making
or decisions about withholding/ withdraving artificial nutrition and hydration.

c.iii The criteria provided in this document for selecting an “appropriate surrogate” should be applied to persons named in these durable powers of attorney.

d. Surrogates named in nondurable powers of attorney:

d.i Do not have legal authority to make decisions of any kind for persons without decisional capacity.

d.ii Although not legally authorized by a nondurable power of attorney, surrogates named in nondurable powers of attorney may still be appropriate surrogates.

e. Court Appointed Guardians

e.i The scope of authority of the guardian in Missouri is determined by the court order.

e.ii If a guardian has been appointed, facilities should request a copy of the court order and make it part of the resident’s permanent record.

e.iii Guardians in Missouri must have “clear and convincing” evidence that they are acting in a manner consistent with the resident’s wishes regarding withholding/ withdrawing artificially administered nutrition and hydration.

e.iv When a guardian has been appointed, before a provider/facility chooses to recognize the decision of a surrogate other than a court appointed guardian, the guardian must be notified of this decision (See section, 8.3.f.).

f. Surrogates recognized by providers/facilities but not appointed by a resident’s advance directive or court order should share in the decision-making process with the physician, family, and representatives of the facility.

g. Ethics committees can assist in resolving conflicts that may arise between various recognizable surrogates and court appointed guardians.

8.4 Surrogate Decision-Making Criteria

a. Substituted judgment decisions: If the providers and surrogate agree that the treatment decision is in accord with the resident’s values and previously expressed preferences, that plan of care should be pursued.

b. Best interest decisions: If the providers and surrogate don’t know or cannot agree about what the resident would choose, then decisions should be based on what reasonable persons in the resident’s position would choose. For example:

b.i In applying the best interest standard to residents who are terminally ill, major considerations are the burden of prolonging dying and whether the resident has the potential benefit of achieving some satisfaction from prolonged life.

b.ii In applying the best interest standard to residents who have a severe and irreversible illness or condition, the decision should
be made by balancing the benefits and burdens to the resident in each case.

b.iii In applying the best interest standard to the resident with an irreversible loss of consciousness, consideration of the benefits and burdens to the caretakers and family are also appropriate.

8.5 Role of Healthcare Providers

a. A provider’s primary responsibility is to the resident.

b. Decisions to forgo life-prolonging treatment must be resident focused.

c. Providers’ responsibilities include

   c.i Fully informing the resident/surrogate regarding the resident’s medical condition and prognosis to the extent information is available and involving the resident/surrogate in the decision-making process.

   c.ii Recognizing and honoring residents’ healthcare treatment preferences.

   c.iii Ensuring that comprehensive and accurate evaluation of the resident’s condition occurs on an ongoing basis.

   c.iv Considering the entire range of reasonable treatment options.

   c.v Considering and conducting therapeutic trials when appropriate.

   c.vi Respecting requests made by the resident/surrogate for additional consultation.

   c.vii Determining whether the loss of decisional capacity is due to temporary or reversible conditions, for example, depression caused by medication.

   c.viii Informing other providers of any decision to forgo or withdraw life-prolonging treatment.

8.6 Role of the Facility

The responsibilities of the facility include

a. Ensuring that appropriate care is provided to residents in accordance with the resident/surrogate’s wishes.

b. Informing residents/surrogates of their rights and promoting those rights.

c. Making reasonable efforts to gather information about the resident’s life, goals and values, medical history, and the existence of any advance directive.

d. Supporting the resident’s right to make autonomous decisions, including the resident’s right to make, change, or revoke advance directives.

e. Ensuring that residents/surrogates have all the available information regarding the resident’s diagnosis, treatment options, risks and benefits associated with various treatment options, and the resident’s prognosis.

f. Verifying that loss of decisional capacity is not due to temporary or reversible conditions, for example, depression caused by medication.

g. Verifying that residents are free from coercion so that they may make an informed and autonomous decision.

h. Having appropriate policies and procedures in place to protect residents’ rights to make treatment decisions.

i. Facilitating consultation with the interdisciplinary care team or ethics
committee when decisions are made to forgo life-prolonging treatment for residents without advance directives or appropriate surrogates.

j. Providing a mechanism for conflict resolution.

8.7 Conflict Resolution

a. Disagreements may arise between resident/surrogate and healthcare providers, among members of the interdisciplinary team, or between the primary decision makers and the facility itself. When such conflict occurs, it is imperative that the parties have access to the widest range of mechanisms to address and attempt to resolve such conflict. These mechanisms include

a.i additional medical consultation;

a.ii care management conferences;

a.iii mental health counseling;

a.iv pastoral counseling;

a.v assistance from the ombudsman program; and/or

a.vi review by an ethics committee.

b. One of the ways a long-term care facility can discharge its responsibilities for supporting residents making these difficult decisions is through the creation and support of an institutional ethics committee.

b.i Ethics committees can assist facilities to address these issues proactively by promoting education about ethics and assisting with policy review and development.

b.ii A primary role of the ethics committee is that of providing a forum where questions and/or disagree-

ments regarding decisions about life-sustaining treatment can be discussed and resolved.

b.iii Committee consultation and review may be undertaken in response to a formal request by a resident, family/surrogate, or provider directly involved in the care of the resident.

b.iv Consultation should be strongly considered in cases in which an appropriate surrogate cannot be identified for a resident without decisional capacity and in cases in which there is persistent disagreement among those responsible for making decisions.

c. Smaller long-term care facilities may consider collaboration with other healthcare provider organizations in order to assemble appropriate resources for the development of an ethics committee.

d. Resolution through litigation should only be an option of last resort.

9. Documentation

9.1 All discussions regarding decisions about withholding or withdrawing life-prolonging medical treatment must be documented in the resident’s medical record.

a. Discussion with residents about their rights to choose or refuse treatment should be encouraged.

b. Staff should be educated to note all such conversations in the resident’s chart; the notation should include what the resident said, when, and with whom the conversation was had.
c. Residents with decisional capacity who state specific treatment preferences should be encouraged to make written advance directives.

d. Procedures should be developed for storing this information so that it is easily retrievable.

9.2 Documentation regarding the process of selecting a surrogate not appointed by the resident is recommended.

9.3 Documentation of a resident’s decisions to forgo life-prolonging treatment should include

a. orders necessary to implement such decisions;

b. the basis for making the decision;

c. the process by which the decision was made, for example, “after consultation with the resident” or “after consultation with the family” or “in consultation with the ethics committee;” and

d. notice that all persons directly involved in the care of the resident have been informed about decisions to forgo life-prolonging treatment.

9.4 If a resident has an advance directive, it must be part of the resident’s permanent medical record. Keep the directives in a designated location within the record to make them easily accessible.

a. Federal legislation and state regulation requires that at the time of admission long-term care residents/surrogates must be informed of their rights to choose or refuse any medical or surgical intervention consistent with state law and of their right to make advance directives.

b. When admitting a resident from the care of another facility, institution, or organization, the long-term care facility should request a copy of any advance directive in the resident’s records at the time of transfer.

b.i The resident/surrogate should be informed that a copy of the directive has been transferred to the facility.

b.ii The resident should be asked to confirm that the document appropriately represents his or her treatment preferences.

b.iii Conversely, when transferring residents to the hospital or to another facility, a copy of their advance directive should be transported with them.

c. It must be noted in the resident’s record whether or not he or she has an advance directive, and if they are presented with a document, facilities must make the document part of the resident’s permanent record. However, so long as a resident maintains decisional capacity, an advance directive has no effect.

d. If the resident is incapable of receiving information regarding advance directives, information about advance directives should be presented to the resident’s surrogate. However, guardians or surrogates may not complete advance directives on behalf of the resident.

e. If a resident regains decisional capacity, information about advance directives should be given to the resident at that time.

f. Facilities should discuss the right of self-determination (including the right to make advance directives) at least annually with all residents who have decisional capacity.
g. Facilities should provide assistance to residents who express interest in completing an advance directive.

h. Although having information provided in an advance directive (particularly the designation of a surrogate in a durable power of attorney for healthcare decisions) is extremely valuable to long-term care facilities, residents may not be required to complete an advance directive.

i. Long-term care facilities are required to develop a process whereby residents with decisional capacity are given an opportunity to review their directives at least annually (13 CSR 15-18.010 [9]).

j. Because of limitations on some older documents, for example, the terminal condition requirement in statutory living wills, facilities should offer to the resident more updated forms of advance directives such as a Health-care Treatment Directive.

k. Residents/surrogates should be informed of new legislation (either state or federal) that may affect their rights to make healthcare treatment decisions.

9.5 Do Not Resuscitate Orders (e.g., DNR Orders, No Code Orders, No Code Blue Orders, Pre-Hospitalized Do Not Resuscitate Request Forms, Outside the Hospital Do Not Resuscitate Request Forms)

a. DNR is a medical order for an individual resident that applies to cardiopulmonary resuscitation (CPR) only.

a.i It requires a physician’s signature after discussion with a resident with decisional capacity. (No other signature is required.)

a.ii The medical record should include the rationale for the decision.

a.iii Residents with decisional capacity should always be involved in DNR decisions.

a.iv DNR orders for persons without decisional capacity should be discussed with surrogates, and families should be informed of a decision to initiate a DNR order and of the rationale for making the order. However, their permission is not required.

a.v If there is no appropriate surrogate and CPR is deemed to be medically futile or clinically inappropriate, a decision to enter a DNR order can be made providing such a decision is within prevailing medical standards.

b. Advance directives and DNR orders are separate documents with separate purposes and one should not be confused for the other.

c. A determination to enter a DNR order may be based on

c.i A resident’s wishes after medical consultation, for example, a resident does not want CPR due to his/her perceived poor quality of life;

c.ii Preferences stated in and consistent with an incapacitated resident’s advance directive;

c.iii Direction provided by a legally authorized agent after medical consultation, for example, durable power of attorney; and/or

c.iv A determination by the physician that the treatment would be futile or clinically inappropriate
for a resident without decisional capacity or an advance directive.

9.6 Transfer Orders

a. A resident/surrogate may request transfer from a long-term care facility at any time and for any reason including a treatment decision that is inconsistent with a policy or the mission of a facility. The facility has an obligation to assist in the orderly transfer of that resident to another facility or location.

b. Residents have a right to refuse hospitalization and residents'/surrogates' requests not to transfer should be honored.

10. General Guidelines for the Care of Dying Persons

10.1 Palliative care should be provided to dying persons.

10.2 Physical care should be directed by a plan of care that recognizes that the resident is dying.

10.3 Areas of special concern are pain medication, nutrition and hydration, and DNR orders.

10.4 Pain medications should support the goals of treatment.

a. Most often when caring for a resident who is terminally ill, the primary goal is to alleviate the pain and suffering of the resident as he or she describes it.

b. Some residents may choose to endure suffering in order to be more alert; other residents may choose to be sedated in order to experience less pain.

c. Addiction to narcotics is not a legitimate concern. Drug dependency is appropriate for a person experiencing persistent pain and is not the same as drug addiction.

10.5 The nutrition and hydration needs of each resident should be based on one's wishes, medical condition, and the goals of treatment as determined by the physician.

a. Food and water should continue to be offered as needed or desired (not just at meal times) to dying persons.

b. Food and fluids should always be provided to any person who requests them. However, it is inappropriate to force feed a resident against his or her wishes. (Force feeding includes syringe feeding.)

c. It is inappropriate to threaten residents with tube feeding if they refuse to eat.

d. Appropriate mouth care is important for persons who are dehydrated.

10.6 Psychological, social, and spiritual needs of residents, families, and care providers are of primary importance and should be addressed in the plan of care.

a. Needs and desires of the dying resident should be the primary concern rather than strict adherence to institutional rules.

b. Staff need to be supported in assisting residents to meet these needs as well as their physical needs.

c. Psychological, social, and spiritual services should reflect the resident/family's expressed wishes.
10.7 Bereavement support should be provided for survivors and caregivers.

a. For the benefit of other residents, it is important to acknowledge death.

b. Staff should have an opportunity to discuss and affirm their feelings about a resident’s death.

c. Residents should also have an opportunity to discuss and affirm their feelings about this experience.

Conclusion
The process that led to the development of these guidelines involved collaboration among many individuals with diverse backgrounds. The guidelines themselves provide relevant ethical, legal, medical, nursing, regulatory, psychological, social, and spiritual considerations to help long-term care facilities develop resident-focused policies concerning life-prolonging treatments. They reflect the importance of a common sense, resident-focused, interdisciplinary team approach to decision making in long-term care facilities. There are no simple solutions to these difficult decisions. The Task Force recommends that the decision-making process in long-term care facilities be expanded beyond legalistic and regulatory concerns to embrace the resident-focused considerations that are set forth in this document.