

ECHO (Extreme Care, Humane Options)
Nursing Facility Recommendations

**Recommendations for
Improving End-of-Life Care
for Persons Residing in
California Skilled Nursing and
Intermediate Care Facilities**

January 2000



The ECHO Nursing Facility Recommendations were produced by the ECHO (Extreme Care, Humane Options) Long-Term Care Task Force in conjunction with the California Coalition for Compassionate Care. Support was provided by grants from Sierra Health foundation and The Robert Wood Johnson Foundation.

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INTRODUCTION

BACKGROUND

In May 1997, a statewide group of healthcare professionals, long-term care associations, state agencies and consumers met to propose ways to improve end-of-life care for residents of California's licensed skilled nursing facilities (SNFs) and intermediate care facilities (ICFs). Known as the ECHO (Extreme Care, Humane Options) Long-Term Care task force, it was convened by Sacramento Healthcare Decisions, a nonprofit organization committed to public participation in improving healthcare policy and practice.

In early 1998, the California Coalition for Compassionate Care was formed to improve end-of-life care throughout California. Supporting the work of the ECHO task force, the coalition proposed that the draft recommendations be field-tested in several nursing facilities. In spring 1999, an educational program on end-of-life decisions was conducted in six skilled nursing facilities that volunteered as pilot sites. Their participation provided a valuable laboratory to test and refine some of the concepts

and strategies contained in this document. Concurrently, the draft recommendations were circulated statewide for review, prior to the final revision by the ECHO Long-Term Care task force in late 1999.

PURPOSE

The purpose of these recommendations is to facilitate institutional processes, enhance provider competence and strengthen organizational relationships to improve two broad domains of end-of-life care:

- ◆ **Advance care planning:** The process of identifying the resident's personal perspectives and values, which – in conjunction with the resident's current and anticipated medical status – provide the basis for making end-of-life medical decisions.
- ◆ **Palliative care services:** Services that provide physical, emotional, psychological, social and spiritual comfort and that together compose appropriate care of the dying person.

In proposing these recommendations, the task force seeks to:

1. Emphasize the role of the resident/surrogate* in the decision-making process.

** In this document, resident/surrogate is a generic term for signifying the resident and/or family member(s), legal guardian, designated surrogate and/or significant others. The specific involvement of any of these people depends on the circumstances of the resident and the issue being addressed.*

2. Assure that SNF/ICF residents receive appropriate, timely and humane end-of-life care consistent with their wishes or, when wishes are unknown, their best interests.
3. Encourage decision-making processes for end-of-life care that are consistent with sound legal, ethical and professional standards.
4. Propose changes in administrative and clinical practices to address existing barriers to appropriate end-of-life care.

These recommendations will benefit:

- Current and future SNF/ICF residents and their families/surrogates.
- Organizations that operate SNFs/ICFs.
- The administrative, physician and nursing leadership within SNFs/ICFs.
- Healthcare professionals and other direct service staff in SNFs/ICFs.
- Federal, state and county agencies responsible for overseeing SNF/ICF care.
- Professional associations that represent SNF/ICF facilities and the personnel who provide residents' care.
- Academic institutions that educate healthcare professionals.

PRINCIPLES

These recommendations are based on important ethical principles:

Patient autonomy

The right of self-determination includes the right of adults to choose among appropriate treatment alternatives and to refuse any treatment offered. To exercise this right in a meaningful way, residents/surrogates must have the necessary information and the opportunity to make an informed decision.

Avoiding harm

Life-sustaining measures may constitute a *harm*, unless the medical benefit to the resident is apparent, is congruent with the resident's preferences, and outweighs the burden to the resident. To maintain an open dialogue, healthcare professionals should discuss all feasible options with the resident/surrogate about the goals of

care, quality of life and desired outcome. Procedures that merely increase the resident's pain, suffering or indignity should not be recommended.

Benefiting the patient

Providing for humane care that supports the dignity of the resident requires far more than avoiding harm. The treatment provided by the healthcare team must be purposefully and conscientiously aimed at meeting the resident's physical, psychological, social, spiritual and emotional needs in an environment of caring and support.

Medical integrity

The goals of care should be to improve the resident's prognosis, comfort, well-being or general state of health; maintain a quality of life satisfactory to the resident; and/or provide comfort, respect and dignity during the resident's remaining days of life. When a physician recommends interventions unlikely to have meaningful benefit to the resident, it may create unrealistic expectations about the resident's prognosis and, at the same time, deprive the resident of humane care at the end of life. Non-medical goals, such as meeting the family's emotional needs, must be recognized and addressed with compassion, while balanced with the principles of responsible and effective clinical practice.

Use of personal and medical resources

Providing treatment without first determining it is beneficial and desired by the resident/surrogate may be fruitless and wasteful. The extraordinary financial cost of prolonged life-sustaining procedures may impoverish residents and their loved ones. These financial burdens to residents/surrogates, and the use of scarce medical resources when meaningful benefit is not evident, are important considerations in evaluating treatment options. These issues should be openly and honestly discussed with residents/surrogates.

RECOMMENDED OUTCOMES AND STRATEGIES

To provide appropriate and humane care for residents near the end of life, several outcomes should be affirmed and promoted in the philosophy, policies and practices of skilled nursing (SNFs) and intermediate care facilities (ICFs).

- Outcome I* Palliative care shares priority with restorative and supportive care among SNF/ICF services.
- Outcome II* Discussions and decisions about end-of-life care are a routine part of the care planning process, and decisions adhere to accepted medical, ethical and legal principles.
- Outcome III* Residents/surrogates are full participants in care planning that considers palliative treatment approaches, as well as supportive and restorative.

Developing and adhering to effective policies and practices that advance these outcomes require the commitment and actions of several important groups:

- A. The corporate, administrative and clinical leadership of SNFs/ICFs.
- B. Healthcare professionals, non-licensed care providers, and public and private conservators.
- C. Regulatory agencies, professional associations and academic institutions.

Recommended strategies for the corporate, administrative and clinical leadership of SNF/ICF:

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| <p>A(1) Develop a written statement of principles or philosophy regarding the institution's role in the provision of end-of-life care that:</p> <ul style="list-style-type: none"> • emphasizes the importance of a team approach to assessing, communicating and delivering appropriate end-of-life care; and • is provided to current, new and potential residents and their families, as well as to staff. <p>A(2) Develop palliative care protocols that define the steps for appropriate pain management, control of distressing symptoms, and maintenance of hygiene and dignity as part of end-of-life care. This includes:</p> <ul style="list-style-type: none"> • providing resources – directly or through referral – for meeting the emotional and spiritual needs of residents, families and caregivers; and • providing hospice care, when feasible, through arrangements with local hospice programs. <p>A(3) Maintain policies and procedures to appropriately identify the surrogate</p> | <p>decision-maker when a resident lacks capacity.</p> <p>A(4) Emphasize in facility policies and procedures the role of the resident/surrogate in the care planning and decision-making process.</p> <p>A(5) Develop and use policies and procedures to establish and document the goal of care for each resident, consistent with the individual's personal perspectives and values.</p> <p>A(6) Use a Preferred Intensity of Treatment form, or equivalent document, as a standard form for the primary care provider* to record the resident's expressed preferences for intensity of treatment.</p> <p><i>* The term primary care provider is used in this document to mean physician, nurse practitioner, clinical nurse specialist or physician assistant when these roles have the equivalent authority for decisions and actions about care of residents. The term physician is used when pertaining only to an MD.</i></p> <p>A(7) Define the expectations of staff performance – through employee job descriptions, orientation/training programs and performance evaluations – related to successfully implementing advance care</p> |
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- planning and palliative care policies and procedures.
- A(8) Integrate current legal and bioethical principles related to end-of-life care with facility policies and procedures on medical and nursing care decision-making.
- A(9) Develop policies and procedures for consultation with a bioethics committee or bioethics professional, especially when addressing situations with complex or unclear ethical choices.
- A(10) Provide education to assist staff in:
- developing skill and comfort in talking with residents and surrogates about end-of-life care;
 - communicating resident's wishes to team members; and
 - understanding pertinent legal and bioethical concepts related to end-of-life care.
- A(11) Establish procedures when residents are transferred to another care setting for also transferring information about their intensity of treatment preferences, personal beliefs and goals, and advance directive documents.
- A(12) Monitor palliative care services and end-of-life decision-making through quality improvement or quality assurance programs.

Recommended strategies for healthcare professionals, non-licensed care providers and public and private conservators:

- B(1) Healthcare professionals use effective and timely communication techniques with residents/surrogates when discussing advance care planning, life-sustaining measures and palliative care.
- B(2) Healthcare professionals involve non-licensed care providers in this communication process and recognize their function as an important link among residents, families and the rest of the healthcare team.
- B(3) Healthcare professionals and conservators develop skill in applying key concepts, such as:

- assessing the decision-making capacity of residents and, if applicable, surrogates;
- understanding the difference between capacity and competence;
- assessing benefit and burden of care; and
- understanding the legal and ethical considerations of withholding and withdrawing life-sustaining measures.

B(4) Healthcare professionals assume that all residents have capacity to make their own decisions unless there is evidence to the contrary. A resident's advanced age or physical or mental disability does not presume a decline in the resident's decision-making capacity (see definition, page 17).

- B(5) Primary care providers, conservators and other professionals understand and apply key concepts critical to the care planning process, such as:
- incorporating residents' personal goals and residents' perception of their quality of life in relation to end-of-life decisions;
 - recognizing the role of residents' cultural, religious and personal values;
 - addressing questions about life-sustaining measures and alternatives; and
 - assisting in resolving conflicts if disagreements arise concerning appropriate plan of care.

- B(6) Primary care providers, when addressing end-of-life issues with residents/surrogates,
- provide resident/surrogate with sufficient information about resident's prognosis and treatment options;
 - provide supporting documentation addressing the clinical status of the irreversibly ill resident;
 - document resident preferences on a Preferred Intensity of Treatment form; and
 - provide medical orders, if needed, specific to the resident's informed end-of-life decision.

- B(7) Healthcare professionals provide palliative care services consistent with the resident’s wishes as determined through the care planning process.
- B(8) Healthcare professionals and non-licensed care providers assure their skills in delivering palliative care meet the needs of residents and their families.
- B(9) Public and private conservators are aware of and support all goals of care (including palliative), the concept of individualized autonomy and the best interest standard.

Recommended strategies for regulatory agencies, professional associations and academic institutions:

- C(1) The California Department of Health Services (DHS) and State and local Long Term Care Ombudsman Programs support palliation as an appropriate goal of care.
- C(2) The California Department of Justice, Department of Health Services, local ombudsmen and local law enforcement agencies appropriately distinguish between criminal neglect and palliative care.
- C(3) Regulatory, professional and academic organizations, healthcare providers and payers use consistent terms related to end-of-life care.
- C(4) California schools of medicine include palliative care within the core curricula of physician education.
- C(5) The California Board of Registered Nursing provides recommendations to California’s schools of nursing, including Advanced Practice programs, for education in end-of-life discussions, decisions and care.
- C(6) The California Association of Medical Directors (CAMD) develops training curricula on care of SNF/ICF residents specifically for physicians and recommends the curricula to nurse practitioner, clinical nurse specialist and physician assistant programs.

- C(7) Regulatory agencies and professional associations encourage and/or provide educational opportunities, materials and policy positions consistent with the need for quality palliative care in SNFs/ICFs.
- C(8) Regulatory agencies, professional associations and academic institutions encourage and/or develop educational programs for their constituents — state surveyors, ombudsman programs, public and private conservators, SNF/ICF leadership, healthcare providers, etc.— on:
 - ethical decision-making processes; and
 - improving communication related to end-of-life care.
- C(9) The California Medical Association supports and sponsors medical education for practicing physicians to enhance their skills in end-of-life care.
- C(10) MDS (Minimum Data Set) vendors modify computer-generated patient care plans to incorporate the goal of care and the resident’s preferences for end-of-life care.

ADVANCE CARE PLANNING

Setting Goals of Care and Interventions for the Last Phase of Life

The purpose of this section is to describe key issues for the SNF/ICF team to consider when incorporating end-of-life decision-making into care planning for residents.

A. MAJOR PRINCIPLES

- ***End-of-life decision-making should be addressed with all residents.***

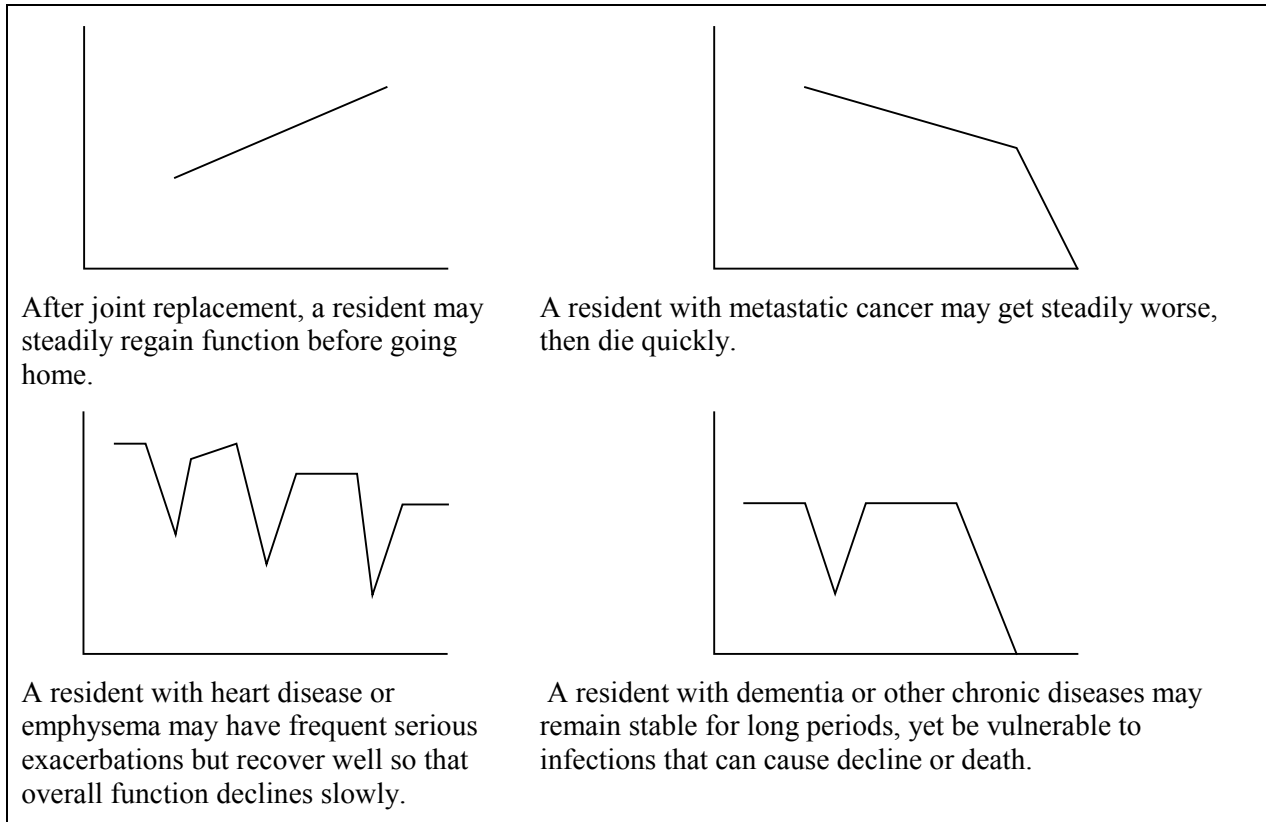
The Patient Self-Determination provisions of OBRA 1990 requires certified facilities to inform residents of their right to make decisions concerning medical care. This includes the right to accept or refuse medical or surgical treatment and the right to formulate an advance directive in order to designate a surrogate decision-maker and/or to express in writing preferences regarding treatment.

- ***Facilitating end-of-life decisions is much more than completing an advance directive.***

Assessing the resident’s goal of care and appropriate interventions will be aided by a resident’s advance directive, but the directive is just one aspect of advance care planning.

- ***For those to whom the nursing facility is their last home, advance care planning should be a regular, routine part of resident-centered care.***

Although prognoses are always uncertain, the primary care provider, facility staff, resident and/or family need to be aware of the course that most likely lies ahead. Some people spend a short time in nursing facilities for rehabilitation prior to returning home. For many others the nursing facility is their last home.



After joint replacement, a resident may steadily regain function before going home.

A resident with metastatic cancer may get steadily worse, then die quickly.

A resident with heart disease or emphysema may have frequent serious exacerbations but recover well so that overall function declines slowly.

A resident with dementia or other chronic diseases may remain stable for long periods, yet be vulnerable to infections that can cause decline or death.

➤ ***Advance care planning doesn't wait for dying to begin.***

The last phase of life may be a period of days, weeks or years, and it can begin unexpectedly. Shaping care for that last phase is the purpose of planning. Although the course of physical or cognitive decline cannot be predicted with certainty, the more the healthcare team knows about a resident—his/her views, values, fears, cultural and religious beliefs, the things that give him/her pleasure—the better the team can respond appropriately and proactively when decisions are needed.

➤ ***Advance care planning usually involves many decisions, over an extended period of time, with unpredictable influences.***

There are no formulas or clinical pathways that lead to a right answer. Virtually every aspect that influences a person's decision about end-of-life care is, in some way, unique to that person. These aspects include:

- The wide variation in how individuals' physical and cognitive functions decline.

- Peoples' differing preferences for care near the end of life – based on culture, religion, personal experience, family relationships, and an individual's own unique views of living and dying.
- People changing their preferences over time. What is an acceptable quality of life at one point may not be later on. Or vice versa.
- Different people involved in the decision-making process over time, as the resident and surrogate shift roles.
- Variation in the type and extent of communication with the resident, as the primary care provider and facility staff trade off taking the lead in their interactions.
- The broad range of end-of-life decisions. This includes decisions about CPR, artificial feeding and hospital transfers. But it can also include more subtle decisions, such as when to stop giving treatments for osteoporosis, doing blood tests or screening for unsuspected cancer or thyroid disease.

B. ESTABLISHING OR RE-ASSESSING THE GOAL OF CARE

➤ ***What is a goal of care?***

A goal of care answers the question “What are we trying to achieve, consistent with this resident's wishes, by providing medical/nursing/supportive interventions?”

➤ ***What are the various types of goals of care?***

In broadest terms, the goals of care are restorative, supportive or palliative (see *Concepts and Definitions*). While some residents are clearly in the nursing facility for rehabilitation, and others for palliative care, most long-stay residents fall into the supportive (maintenance) category. These terms are very similar to those described in HCFA's RAI Version 2.0 Manual, Chapter 5 (Linking Assessment to Individualized Care Plans): “there may be one or more types of goals for each resident, such as improvement goals, prevention goals, palliative goals or maintenance goals.”

Keep in mind, however, that broad categories such as restorative, supportive or palliative care are not individualized and may not provide adequate guidance for decision-making. A sentence that captures the resident's values and preferences for end-of-life care is often clearer and more descriptive. For example, a resident may say, “I believe life is sacred and that I should try to live as long as possible even if I am suffering and battling nearly impossible odds.” This expression of the resident's values provides a much clearer message about his/her goal of care than does the term supportive.

Sometimes even personal expressions fall short of giving clear guidance. A resident may say, “I would prefer to go in my sleep. I certainly wouldn't want to be kept alive on machines.” Although this resident would not want prolonged life support, she has not stated her goals in a positive sense so many questions

remain about other interventions. Most residents in the palliative category would agree with the more specific goals of preserving dignity and preventing any unnecessary suffering, but even in this category there may be important individual differences. The team should encourage the primary care provider, nursing and social work staff, and others to document a resident's personal expressions that reflect actual goals and preferences.

➤ ***When should the goal of care be determined?***

The goal of care should be discussed or reviewed:

- On admission to the facility;
- During quarterly care planning;
- Any time there is significant change in the resident's physical or mental condition; and
- When requested by the resident/surrogate.

During routine care conferences ensure that the overall goal of care is clear and that orders and documentation are appropriate. Facilities need to develop a format to do this that best fits with their own care planning practices.

➤ ***Who should participate in setting the goal of care?***

This is the responsibility of the interdisciplinary team (IDT) which would include the resident, resident's family or surrogate, attending physician, registered nurse with responsibility for the resident, and other appropriate staff as determined by the resident's needs. Facilities promote participation of the resident/surrogate by:

- encouraging their attendance at care planning conferences and
- scheduling care planning conferences at a time of day that is convenient for residents/surrogates.

If the resident/surrogate is unable or unwilling to participate with the IDT directly, the physician should ascertain and communicate the values and preferences of the resident/surrogate to the team.

The resident's situation may change rapidly and repeatedly, and formal planning cannot always be done in a timely manner. In such cases,

information from prior deliberations can be shared with the resident/surrogate, primary care provider and other members of the IDT as the medical situation changes.

➤ ***What information is needed to determine the goal of care?***

Clinical Information

- Diagnoses and prognoses, including current and anticipated functional status;
- Treatment options with their respective clinical benefits and burdens for the resident; and
- Current decision-making capacity of the resident.

Personal and Social Information

For residents with full decision-making capacity, this includes the resident's:

- Current understanding of his/her health condition and prognosis;
- Values and treatment preferences, including his/her beliefs about the chances for recovery;
- Written/verbal statements of preferences or values, including an advance directive;*
- Cultural factors and religious or personal beliefs relevant to preferences about end-of-life care; and
- Pertinent information from family members or significant others.**

** Although an advance directive is not in effect while the resident has appropriate decision-making capacity, reviewing a completed document can provide the team with additional information about the resident's values and goals.*

*** Information from family members or significant others does not override the views of a resident with decision-making capacity and should be considered advisory.*

For residents without full decision-making capacity:

- Surrogate's current understanding of the resident's health condition and prognosis;

- What is known about the resident’s previously expressed values and priorities, as indicated in advance directives or other written/verbal statements of preferences, including cultural factors and religious or personal beliefs;
- The resident’s relevant verbal and physical expressions; and
- The perspectives of family members or significant others.

➤ ***How is the goal of care determined from this information?***

Once the core information (described above) has been obtained, the IDT reviews the clinical factors (prognosis, what is medically possible, the risks and benefits of treatment options) and how they correspond with the resident's preferences and values. Once fully informed with accurate, realistic medical information, the resident/surrogate is the primary decision-maker about his/her own goal of care.

When a person is admitted to a SNF to recover (for example) from a hip replacement, the goal of care is usually restorative. In other situations, physicians and nursing facility staff can help the resident/surrogate identify the goal of care by asking:

- What are you hoping will happen?
- What are we aiming for?

Some residents/surrogates may be ready for such questions as:

- Have you thought about what you would like the last phase of your life to be like?
- What is most important for you during this time?

The care planning process needs to be sensitive to the potential need to shift the overall goal of care – for instance, moving from supportive to palliative – when appropriate.

C. RELATING THE GOAL OF CARE TO SPECIFIC INTERVENTIONS

➤ ***How does knowing the overall goal of care help in making decisions about treatment?***

Establishing an overall goal of care helps the team arrive at a holistic view of the resident, and it helps the resident/surrogate and the team make decisions about specific interventions. However, the team needs to be careful not to insist that the goal of care and decisions about possible interventions always be consistent. The resident may choose to have an intervention that doesn’t fit with the overall goal of care. If team members feel this choice clashes with an ethical principle, they should seek additional resources as discussed below. Discussions about specific interventions often clarify the goal of care and may generate new information leading to reconsideration of the goal.

➤ ***How do we know a certain intervention will be appropriate since the goals of care are so broad?***

For the majority of residents, decisions about whether to initiate or continue any particular

medical intervention (from routine lab tests or medications, to invasive treatment such as dialysis or CPR) ultimately depend on whether the *benefit* of receiving the intervention will be greater than the *burden* of the intervention to the resident (see definition, page 16).

For some residents, any intervention that sustains life will always have greater benefit than burden. The personal, cultural or religious beliefs of that resident may clearly indicate that prolonging life always has the highest priority regardless of the suffering involved. For others, however, balancing benefit and burden is a continuous, dynamic process that doesn’t lend itself to strict protocols.

The perception of burden and benefit is subjective and usually can only be assessed in the context of the resident’s desires about his or her last phase of life and own assessment of his/her current and future quality of life.

(A simple example of assessing benefit and burden is described on page 11.)

Questions the IDT can ask:

1. Why are we doing this?

Every intervention should be assessed in terms of how it will aid the resident in achieving his/her personal preferences for living the last phase of life.

2. If we are not sure if this approach is appropriate for this person at this time, what else do we need to know that will make it clearer?

If a resident is unable to indicate his/her views about possible changes in his/her quality of life, consider the resident's previous experiences and expressions when weighing the benefit and burden of the approach. Consider using additional resources as noted below.

3. If this intervention seems appropriate now, when do we need to re-evaluate our approach?

Based on the resident's views about his/her quality of life, identify those aspects (e.g., capacity for autonomous decision-making, social interaction, independent activity) that the intervention or a change in medical condition may adversely impact.

➤ ***Aren't end-of-life decisions sometimes difficult or controversial?***

Most end-of-life decisions in nursing facilities are not controversial or complex because:

- Residents may stay in nursing facilities for extended periods, enabling good communication to develop about residents' values and preferences; and
- Most residents and family members recognize that the last phase of life is at hand and are more willing and able to discuss this subject openly.

At times, however, determining if a certain approach is appropriate can be difficult and troubling. Sometimes disagreements arise when information is inadequate or communication poor among the team members. At other times conflicts exist because there is an ethical dilemma: a clash of ethical principles for which there may not be a right answer. Conflicts may

arise among and between the healthcare team and resident/surrogate when:

- The resident's wishes are unknown and surrogates are not in agreement about end-of-life decisions,
- Surrogates have expectations about the goal of care that the healthcare team feels cannot be met,
- A member of the healthcare team disagrees with the goal of care or a particular medical intervention, or
- One or more key decision-makers are unclear or disagree about ethical, legal or medical principles that pertain to this situation.

➤ ***How should these situations be handled?***

In the hospital setting, many hospital ethics committees have developed a formal case consultation process. This is composed of data-gathering followed by structured discussion among committee members, appropriate members of the treatment team and the patient's support system. The committee then makes non-binding recommendations. The process seems to work best when the committee is interdisciplinary, including non-clinical members, and when committee members work together as a team, respecting the differences among them.

Some nursing facilities have developed ethics committees, but in facilities without one, it is advisable to use other resources—such as an outside physician, an experienced bioethicist, a local bioethics committee, or an attorney—to assist the team in reaching agreement. This is also useful when the team has reached agreement but would like an independent outside opinion.

CASE EXAMPLE

Assessing Benefit and Burden

Mrs. Agnes Cole is an 84 year-old woman with diabetes and a history of multiple strokes that have led to her dementia. Several months ago, a stroke left her immobile, mute and unable to recognize or respond to her family members or the facility staff. Mrs. Cole's daughter and her physician have had several discussions about the prognosis and treatment options. During a recent care planning meeting, IDT members asked Mrs. Cole's daughter (the designated surrogate) to consider what Mrs. Cole might want if another severe medical event occurred. Based on Mrs. Cole's prior expressed wishes and poor prognosis, her daughter, the IDT and the physician agreed that her goal of care was palliative.

Several weeks later, Mrs. Cole developed a temperature of 100.5 F and became short of breath. Her care plan indicated that she was not to be provided with treatments to prolong her life but that medical treatments should be provided to keep her comfortable.

To clarify Mrs. Cole's clinical situation, the physician ordered laboratory tests and a chest x-ray. These revealed a pneumonia which could be treated with antibiotics. At that point, the physician, nurse and daughter had to weigh the *benefit and burden* to the resident of the different treatment options:

1. Transferring her to the hospital for antibiotics and any other life-sustaining treatments that might be needed;
2. Treating the pneumonia with antibiotics in the nursing home, but without transferring her to the hospital; or
3. Not treating the pneumonia but making her comfortable with medications to relieve her shortness of breath and fever.

The nurse contacted the daughter and the physician to discuss the treatment options and how the options would contribute to her goal of care. They agreed that it was best to make her comfortable with medications in the nursing facility but not to treat the pneumonia. In coming to this decision, they considered the following:

- Mrs. Cole had indicated several years ago that if she could no longer interact with her family she would not want any medical treatment to prolong her life.
- Even if the pneumonia were successfully treated, it would not return her to the quality of life that Mrs. Cole had said was worthwhile to her.
- They could ease her fever, discomfort and shortness of breath without using antibiotics.
- They could keep her in the nursing facility for her final days, being cared for by those who know her well.

GETTING STARTED

The recommendations in this document are intended as a blueprint that facilities can modify and adapt according to their institutional culture, processes, resources and interests. With end-of-life care, the critical issue is not only "what needs to be done?" but also "where do we start?"

The following are suggestions that may prove helpful:

1. Secure the commitment of the facility administrator, director of nursing and medical director.

The administrative team ultimately makes the difference in implementing changes in policy and practice. Although this commitment does not require an open-ended timeframe or unlimited resources, it does require that the administration endorse and support those charged with planning changes.

2. Designate a small—and enthusiastic—leadership team.

Appoint a team leader to convene a multidisciplinary Quality Improvement Team to assess the needs of the facility, establish priorities and develop an implementation plan. In addition to representatives from the nursing, dietary and social services departments, the team might also include a chaplain, a family member and the ombudsman.

3. Conduct an internal assessment.

To develop a plan uniquely suited to the facility, first identify its strengths and weaknesses.

Consider:

- Evaluating the status of current written processes and procedures using the tool "Assessing Your Facility's Policy and Practice of End-of-Life Care;"
- Soliciting current opinions, comments and/or concerns regarding end-of-life issues with staff, resident council, family council, medical director and ombudsman;
- Reviewing the facility's compliance with the Patient Self-Determination Act; and
- Reviewing recently closed charts of residents whose death was expected. Were the goals of care and end-of-life preferences documented and respected? Were there problems with pain, dyspnea or other distressing symptoms? Were psychological

and spiritual needs assessed and addressed? Was communication effective with loved ones? Were they satisfied with the care? Were all appropriate disciplines involved?

4. Establish and prioritize objectives for improvement.

Based on the internal assessment, identify two to four aspects of end-of-life care to be improved over the next year. Though the assessment may reveal many more needs than that, sustainable change is difficult if too much is undertaken at once. Begin with quick-start projects that will generate enthusiasm, rather than an arduous project like rewriting all the policies at once. Stay realistic while raising the bar of expectations one notch at a time.

5. Include infrastructure changes whenever possible.

Educating staff is often a reasonable first intervention. But education alone rarely leads to lasting change in clinical behavior, particularly in an area as complex as end-of-life care. For each targeted area, identify specific changes that may be needed in the institutional structure. These infrastructure changes may include such things as:

- Revising the orientation and inservice programs;
- Adopting a pain assessment protocol;
- Tracking end-of-life-related indicators in QA meetings;
- Updating job descriptions; and
- Using a form to document treatment preferences.

6. Take incremental steps, but make them visible.

Though the steps may be small, they should be visible and measurable. Once actions are chosen, develop a QA monitoring tool to identify areas

of success or opportunities for improvement. Recognize success and give credit to those making a difference, however minor. As soon as one change is working, choose another. The impact of these changes will grow over time.

7. Establish responsibilities and a timeline.

For each goal or action, decide who is responsible, how often and in what context they will visit the issue, and the date for expected completion or re-evaluation. Allow a reasonable amount of time to effect change.

8. Collaborate with colleagues from other facilities and regions.

Talking with others and sharing ideas, policies and educational programs will save countless hours and sustain creativity. Seek out or form regional networks for support.

ASSESSING YOUR FACILITY’S POLICY AND PRACTICE OF END-OF-LIFE CARE

Improving your facility's end-of-life practices begins with assessing them. Though individual clinicians and support staff may deliver excellent end-of-life care, practices must become institution-wide and consistent over time. Sound principles, policies and practices—well-documented in administrative and clinical protocols—provide the foundation for developing competence and monitoring improvements.

Assessing your facility provides a means by which strengths and weaknesses can be identified,

improvements prioritized, and a baseline established from which to measure change. This assessment, however, does not measure the extent to which these policies are followed; it only identifies whether the policy exists. How to use this information is the next step in the planning process. It may be helpful for several people to complete this assessment independently (e.g., director of nursing, staff developer, administrator, medical director) and then compare notes.

Administrative policy

	Yes	No
A. Is there currently a written statement of the facility’s principles or policy regarding care for residents at the end of life?		
B. If so, does it address:		
1. Respect for resident/surrogate preferences?		
2. Respect for residents’ cultural, religious and personal values?		
3. On-going resident/surrogate’s participation in care decisions?		
4. Assistance in completing advance directives?		
5. Withholding and withdrawing life-sustaining measures such as artificial nutrition?		
6. Decision-making capacity?		
7. Identification of surrogate?		
8. Ongoing communication with resident/surrogate?		
9. Transferring documentation of resident/surrogate preferences when the resident moves to another level of care?		
C. Is this policy provided to:		
1. Staff?		
2. Residents?		
3. Families/Surrogates?		

Clinical policies and practices

	Yes	No
A. Does the written care planning process include:		
1. Establishing and documenting the goal of care for each resident, consistent with resident’s personal preferences or values?		
2. Reviewing the goal of care and resident preferences as needed?		
B. Are there palliative care policies for:		
1. Assessing and managing pain?		
2. Managing distressing symptoms such as dyspnea, anxiety, constipation, and fatigue?		
3. Providing resources for meeting the emotional needs of residents/surrogates?		

	Yes	No
4. Providing resources for meeting the spiritual needs of residents/surrogates?		
5. Arranging for hospice care when appropriate?		
C. Are there standardized forms for:		
1. Documenting preferred intensity of treatment (e.g., the PIT form)?		
a. If so, are these forms reviewed during care planning meetings for current appropriateness?		
2. Assessing pain status and effectiveness of interventions?		

Education

	Yes	No
A. Are there educational materials available for residents/surrogates on decision-making and care for those near the end of life?		
B. Does on-going inservice education (for CNAs , RNs, LVNs and SWs) include:		
1. Basic knowledge of ethics, law and regulation pertaining to end-of-life decision-making?		
2. Communication skills for facilitating end-of-life decisions?		
3. Pain assessment and management?		
4. Non-pain symptoms and complications such as fatigue, constipation?		
5. Hydration and nutrition issues?		
6. Promoting dignity, relationships, and a sense of control at the end of life?		
7. Cultural, religious, and spiritual aspects of palliative care?		
8. Decision-making capacity?		
9. Team issues in end-of-life care, including the role of pastoral care?		
10. Role of hospice team in nursing facilities?		

Monitoring

	Yes	No
A. Are the expectations of staff for quality end-of-life care defined in:		
1. Job descriptions?		
2. Performance evaluations?		
B. Have quality assurance mechanisms been established for:		
1. Documenting completion of and compliance with advance directives?		
2. Monitoring delivery of palliative care, such as pain control, management of distressing symptoms, etc?		
3. Transferring resident/surrogate preferences across settings?		
C. When residents are transferred to acute care, is there a routine quality review to assess appropriateness of transfer?		
D. Are residents' deaths reviewed to assess quality of care at the end of life?		

Resources availability

	Yes	No
A. Are the following resources available when needed:		
1. Hospice services?		
2. Pastoral care?		
3. Ethics committee or ethicist consultation?		
B. Is there written instruction on how these resources can be obtained?		
C. Are these instructions provided to residents/surrogates?		

Appendices

CONCEPTS AND DEFINITIONS

Words and their meanings are presented here to foster common understanding of these recommendations and other materials related to end-of-life care and to encourage consistency in how these terms are used.

GOALS OF CARE

Restorative: Medical, nursing and support services are aimed at restoring residents to a previous, higher level of functioning.

Supportive: Medical, nursing and support services are aimed at maintaining the resident at his/her existing level of functioning, when restorative interventions are no longer possible or desired. A supportive goal of care requires regular assessment of the resident's medical status and personal preferences to assure that the burdens of treatment do not outweigh the benefits.

Palliative: Medical, nursing and support services are aimed at ensuring maximum comfort and dignity during the last stages of life. The emphasis is on controlling pain, relieving symptoms, preserving dignity, and providing emotional and spiritual support for resident and family. (Interventions with a palliative purpose may also be appropriate for residents when the goal of care is restorative or supportive).

OTHER TERMS USED IN THIS DOCUMENT

Advance Care Planning: The process of identifying the resident's personal preferences and values, which – in conjunction with his/her current and anticipated medical status and goals – provide the basis for making decisions about end-of-life care.

Advance Directive: This is a written instruction – such as California's Durable Power of Attorney for Health Care or Natural Death Act Declaration – that relates to the provision of healthcare. It allows individuals in advance of medical treatment to state choices for medical treatment and/or designate someone (a surrogate or proxy) to make decisions on their behalf when they no longer can. Additionally, there are non-statutory documents or written statements of preferences that are considered *advisory* advance directives.

In July 2000, the aforementioned provisions are repealed and replaced by the new Health Care Decisions Law (AB 891, Stats. 1999, ch. 658). AB 891 recasts the provisions and specifies that an individual having capacity may give an individual healthcare instruction either written or oral or a power of attorney for healthcare authorizing the agent to make healthcare decisions and also including individual healthcare instructions. In addition, the Health Care Decisions Law defines a legally sufficient healthcare directive, specifies that an agent shall make a healthcare decision in accordance with the principal's healthcare instructions and that the agent who is known to the provider be willing and available to make such decisions.

All existing durable powers of attorneys for healthcare, conservatorships, living wills, and other related documents authorizing healthcare treatment that were executed prior to July 1, 2000 remain in effect and are not required to be rewritten in order to be effective and legally valid.

Benefit vs. Burden: This standard has arisen in the context of life-sustaining procedures – which ones and for how long their use must be maintained – and involves determining whether the proposed treatment is proportional or disproportional in terms of the benefits to be gained versus the burdens caused. Under this approach, proportional treatment is that which, in the views of the resident, has at least a reasonable chance of providing benefits to the resident that out-weigh accompanying burdens.

For example, if a proposed treatment is extremely painful or intrusive but promises complete cure or significant improvement, it would be considered proportionate. In contrast, if a proposed treatment course is only minimally painful or intrusive but carries no hope for significant improvement, it would be considered disproportionate.

Burdens of treatment may include increased pain, discomfort, reduced mobility, inconvenience, other

risks, or prolongation of the dying process. If the resident is unable to assess the benefit-burden for him/herself, the surrogate may do so by following the resident's expressed desires if known or what is in his/her best interest, if the resident's views are unknown.

Best Interest Standard: This applies when the resident's desires are unknown or unclear. It involves considering such factors as the relief of suffering, preservation or restoration of functioning and quality as well as extent of life sustained. The surrogate might also take into account the decision's impact on those people closest to the resident.

Care Planning: This is the process used to arrive at an individualized, resident-centered plan of medical, nursing and supportive care that reflects the resident's clinical condition/prognosis, personal views and values. Although the product of this process (the care plan) is commonly developed according to a defined schedule, it may be modified as necessary to reflect the changing needs and desires of the resident.

Comfort Care: This is often synonymous with the term *palliative care*. The primary goal is to enhance the resident's quality of life by actively treating physical pain and discomfort, meeting the emotional and spiritual needs of resident/family, and fostering an environment of dignity and respect during the last phase of life. Specific comfort care interventions are based on the resident's individual needs and desires.

Competence: A person is legally presumed to be competent to have the ability to make a variety of decisions about oneself unless the courts revoke that ability.

Decision-Making Capacity: This is the ability to make and communicate choices that reflect an understanding and appreciation of the nature and consequences of one's decisions. Decision-making capacity is often not static or absolute; it can vary from day-to-day, and residents can have capacity for some types of decisions and not for others. A person is presumed to have capacity to make healthcare decisions unless the attending physician, in consultation with the IDT, family members and/or close friends, determines that the person is incapacitated.

End-of-Life Care: This refers to the medical, nursing and supportive services that are provided to

residents during their last phase of life. These services address particular physical, emotional, spiritual and psychosocial needs that may be especially significant during this time.

Life-Sustaining Measures: These are healthcare interventions whose primary purpose is to prolong life and delay the resident's dying. These can include, but are not limited to, CPR, artificial nutrition and hydration, use of ventilator, dialysis, antiarrhythmics, etc.

Non-Licensed Care Providers: These are non-licensed staff of SNFs/ICFs who provide a service which brings them in contact with residents on a regular basis (e.g. CNAs, chaplains, activity leaders)

Preferred Intensity of Treatment Form (PIT): This document describes the resident's treatment preferences based on communication between the physician and resident/surrogate.

Primary Care Providers: These include physicians, nurse practitioners, clinical nurse specialists and physician assistants who have the primary responsibility for overseeing the medical care and writing orders for residents.

Quality of Life: An individual's perspective of his/her present state of life. This perspective is personal, subjective and individualized, and can best be assessed by the individual him/herself. If the individual can no longer communicate this perspective, then a surrogate acting on behalf of the individual may assess quality of life. In doing so, the surrogate must follow the previously expressed wishes, values or points of view of the individual, or, if those are unknown, what is in the individual's best interest. Quality of life is most relevant when weighing the benefit vs. burden of certain types of medical treatment. Treatment decisions must promote care that respects personal choice and preserves dignity.

Surrogate/ Surrogate Decision-Maker: This is an individual who participates in healthcare decision-making on behalf of an incapacitated or incompetent resident. The surrogate may be formally appointed (by a Durable Power of Attorney for Health Care or by a court) or, in the absence of a formal appointment, may be recognized by virtue of a relationship with the resident.

NOTE: Pages 18-26 were not produced by the ECHO task force but are included here as reference material. This section was written in May 1998 and some of the terms used may differ from those in the ECHO recommendations.

PROCESS: USING THE PREFERRED INTENSITY OF TREATMENT FORM

IMPORTANT INFORMATION ABOUT THE PIT POLICY

The Long Term Care Bioethics Consortium of the East Bay developed the attached policy as part of its Kaiser Innovations project, Moving the Preferred Intensity of Treatment (PIT) Form into Practice. The Consortium consists of individuals from skilled nursing facilities, acute care hospitals, senior service agencies, professional and consumer groups in the Northern Alameda County area. The mission of the Consortium is to provide ethics resources to individuals and institutions involved in long term care in the areas of policy development, education, and consultation. The California Medical Association developed the PIT form in conjunction with other professional groups. The Department of Health Services has reviewed the policy and the PIT form and supports, but does not mandate, their use.

You should know the following:

- This policy does not reflect any new Title 22 or HCFA requirements.
- This policy is not mandated by Title 22.
- This policy supports use of the PIT for physician (nurse practitioner or physician assistant) documentation as the equivalent to a physician progress note.
- This policy does not support the use of the PIT as a physician's order sheet or as a patient's advance directive.
- This policy may be useful to you in meeting existing requirements for physician documentation and communication of patient preferences.
- The documentation of treatment preferences by the physician on the PIT form should be integrated into the total plan of care and guide the decision making process.
- The goal of this policy is to ensure that resident's preferences are known and available and serve to guide the medical decisions made in every care setting—at the SNF or when transferred to another level of care.

Procedures for Documenting and Transmitting Intensity of Treatment Preferences

Rationale

As set forth in federal law and Title 22, Division 5, Chapter 3, California Code of Regulations, residents of this skilled nursing facility (SNF) have the right to accept or refuse medical treatment. Importantly, our residents have the right “to consent or refuse any treatment or procedure,” including life-sustaining treatments or procedures. (Title 22, Section 72527)

When residents’ intensity of treatment preferences are expressed to physicians, those preferences should be documented in the resident’s health/medical record. When the resident is transferred, intensity of treatment preferences should be transmitted to other health care facilities.

This document establishes our protocol for: (1) physician documentation of intensity of treatment preferences expressed by SNF residents, and (2) the transmission of such documentation to other health care providers.

Documenting Intensity of Treatment Preferences

Prior to SNF resident admission, upon resident admission, or subsequent to resident admission, resident intensity of treatment preferences should be addressed. Facility staff may assist in educating residents and in gathering information pertinent to residents’ intensity of treatment preferences. This information should be made available to the physician. Physicians (or designee*) should document a resident’s expressed intensity of treatment preferences. Such physician documentation may include, but is not limited to:

1. Physician’s Documentation of Preferred Intensity of Treatment (PIT) Form
Facility staff may encourage physicians to complete and sign the Physician’s Documentation of Preferred Intensity of Treatment (PIT) Form.
2. Pre-Hospital Do Not Resuscitate (DNR) Form
Facility staff may assist residents, resident surrogates, and physicians in completing the Pre-Hospital Do Not Resuscitate (DNR) Form, if appropriate.

Transmitting Intensity of Treatment Preferences

Upon resident transfer to another site of care (e.g., acute care facility, board and care home, intermediate care facility), facility staff shall send to the new site of care copies of the resident’s advance directives, most recent PIT Form, and a copy of the Pre-Hospital Do Not Resuscitate (DNR) Form, if available.

**As permitted by law, a nurse practitioner or physician assistant may assume part of the physician’s responsibility.*

<h2 style="margin: 0;">Physician's Documentation of Preferred Intensity of Treatment (PIT) Form</h2>
--

The PIT Form is an optional form that we recommend to physicians. When used, the PIT Form is to be completed by the physician (or designee) and reflects a resident's (or as expressed by the surrogate decision-maker) treatment preferences. The facility recognizes that the PIT Form is not an advance directive. The PIT Form is documentation and has the legal standing of a physician progress note. It is expected that the resident's condition will be reviewed periodically and that the physician (or designee) will amend or rewrite the PIT Form if new data become pertinent. Note: The PIT Form is not witnessed by an ombudsman. The procedure for filling out the PIT Form is as follows:

<u>SECTION</u>	<u>PROCEDURE</u>
1. Discussion	The PIT Form is to be completed by the resident's attending physician (or designee) after discussion with the resident or resident's legally empowered surrogate decision-maker. Per this section the physician (or designee) must indicate that s/he has discussed with the resident: 1. Pertinent diagnoses, 2. Treatment options, and 2. Prognoses.
2. Mental capacity	Here the physician (or designee) must indicate the resident's mental capacity to understand the nature and consequences of the resident's diagnoses and the treatment options discussed.
3. Other documents	Any available advance directives or pertinent documents should be reviewed by the physician (or designee) and placed in the resident's chart if available. Advance directives and pertinent documents would include but not be limited to: 1. Durable Power of Attorney for Healthcare (DPAHC), 2. California Natural Death Act Declaration, 3. Court orders, 4. Certified letter of guardianship or conservatorship.
4&5 Preferences	<u>Any</u> verbal or written expression of the resident's desires should be indicated in sections 4 and 5 of the PIT Form.
6. Medical conditions	In this section, the physician (or designee) indicates medical conditions which are pertinent to the resident's intensity of treatment preferences.
7. Overall treatment goal	In consultation with the resident/surrogate, the physician (or designee) chooses among the three treatment goals: 1. Restorative care, 2. Supportive care, or 3. Palliative care.
8. Intensity of treatment	In consultation with the resident/surrogate, the physician (or designee) specifies intensity of treatment/intervention in the following areas: 1. Cardiopulmonary resuscitation, 2. Hospitalization, 3. Intravenous fluids, 4. Medically provided nutrition, 5. Antibiotics, 6. Other, as applicable.
9. Place in chart	The completed PIT Form shall be placed in the resident's medical record.
10. Other orders	"No CPR" <u>must</u> be written as an order. Valid Do Not Resuscitate (DNR) orders written as transfer orders will be accepted by the facility at time of transfer. [See attached 02/12/96 memo from Department of Health Services for description of valid DNR orders.] Although orders are not required for other treatment limitations, an order such as "no hospitalization" may be written for additional clarity.

Pre-Hospital Do Not Resuscitate (DNR) Form

The Pre-Hospital Do Not Resuscitate (DNR) Form instructs emergency medical service (EMS) personnel to forgo prehospital resuscitation attempts in the event of a patient's cardiopulmonary distress. Prehospital settings include, but are not limited to: a patient's home, a skilled nursing facility, and an ambulance.

The Pre-Hospital Do Not Resuscitate (DNR) Form instructs EMS personnel to not initiate chest compressions, assisted ventilation, endotracheal intubation, defibrillation, or cardiotoxic drugs in prehospital settings.

When used in this facility, the Pre-Hospital Do Not Resuscitate (DNR) Form must be signed by the resident or appropriate surrogate decision-maker. The resident's physician also must sign the form.

NOTE: OTHER FACILITY SPECIFIC "DNR" FORMS MAY EXIST BUT ONLY THE PRE-HOSPITAL DNR FORM WILL BE HONORED BY EMS PERSONNEL

To order additional copies of the Physician's Documentation of Preferred Intensity of Treatment (PIT) Form or the Pre-Hospital Do Not Resuscitate (DNR) Form, contact:

CMA Publications, Inc.
P.O. Box 7690
San Francisco, CA 94120-7690
Telephone: (415) 882-5175

DEPARTMENT OF HEALTH SERVICES

LICENSING AND CERTIFICATION

1800 THIRD STREET, SUITE 210

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February 12, 1996

TO: SKILLED NURSING FACILITIES
INTERMEDIATE CARE FACILITIES
GENERAL ACUTE CARE HOSPITALS (DISCHARGE PLANNERS)

SUBJECT: TRANSFER OF DO NOT RESUSCITATE (DNR) ORDERS FROM AN
ACUTE CARE HOSPITAL TO A NURSING FACILITY

This letter is intended to clarify the Department of Health Services' position regarding the transfer of Do Not Resuscitate (DNR) orders from an acute care hospital to a nursing facility.

It has come to our attention that there may be some confusion among physicians and nursing facility staff regarding whether or not DNR orders can be transferred from an acute care hospital to a nursing facility. The confusion appears to stem from a misinterpretation of both the federal self-determination provisions of the Omnibus Budget Reconciliation Act of 1990 (OBRA) and the state's requirements for orders upon admission.

The Department is aware of no state or federal law or regulation that prohibits DNR orders from being transferred from one level of care to another. Although it is a standard of practice in the community, and in most health facilities, that orders are part of a facility's record and do not generally "transfer," the state's regulations do not require that new orders be immediately written upon admission. In fact, we know of nothing that would prevent a facility from developing written patient care policies and procedures to allow for the transfer of orders from the acute care hospital as part of their physicians' services policies. This includes the transfer of DNR orders.

If a nursing facility's policies and procedures allow for the transfer of DNR orders, the nursing facility must be assured that the DNR order being transferred is valid (see California Code of Regulations, Section 72528(c): "...the facility shall also ensure that all decisions concerning the withdrawal or withholding of life sustaining treatment are documented in the patient's health record.") The following criteria, taken from

the Department of Health Services' Guidelines Regarding Withdrawal or Withholding of Life-Sustaining Procedures(s) in Long Term Care Facilities (December 14, 1988), should be met when determining the validity of a DNR order:

- clear written evidence of the patient's medical diagnosis, condition, and prognosis;
- if the patient lacks capacity, a determination by the attending physician that there is not a reasonable possibility of return to cognitive life (after consultation with the surrogate decision maker);
- a clear statement by the primary treating physician that the patient was fully informed by the physician of the consequences of withdrawal or withholding of life-sustaining procedures. If the patient lacks capacity, a statement by the attending physician that the surrogate decision maker has been fully informed by the physician of the consequences of withdrawal or withholding of life-sustaining treatment; and
- any indicator of the patient's desires, including, but not limited to, a Durable Power of Attorney for Health Care, Directive (now termed a Declaration) pursuant to the California Natural Death Act, "living will," or a physician recording of desires verbally expressed by the patient. In those cases in which the patient's desires are not known, documentation that a surrogate decision maker has been guided by the patient's best interests.

If the above criteria are met, then the DNR order is considered to be a valid order which can be followed, unless contraindicated, consistent with the facility's policies and procedures (California Code of Regulations, Section 72301 (f)). However, it should be pointed out that a DNR order is not an "Advance Directive," as that term is defined, since it is not completed by the patient. An advance directive is a statutorily recognized statement of the patient's wishes regarding medical treatment, such as a Durable Power of Attorney for Health Care (DPAHC), or a Declaration pursuant to the Natural Death Act. It may also be a non-statutorily recognized statement from an individual (such as a "living will") which is completed by the individual himself. The physician's DNR order documents the patient's wishes or the best interests of the patient, regardless of whether or not any advance directive exists that was completed by the patient.


Both types of documentation--the advance directive and the physician's order--can transfer with the patient. However, federal law and regulations (the patient self determination provisions of OBRA 1990) require certified hospitals and nursing homes to ask each adult patient or resident, upon admission, if they have executed an advance directive and provide the patient or resident with information on the right to formulate one under state law. The facility shall not, however, condition the provision of care or otherwise discriminate against a patient based on whether or not the patient or resident has executed an advance directive. To this extent there must be some dialogue between the health facility and the patient or resident (or, if incapacitated, the patient's surrogate decision maker).

A patient with medical decision-making capacity can discuss his or her wishes with the physician and have his/her wishes expressed in the physician's orders, without the need to complete an advance directive. A patient with medical decision-making capacity can also choose to complete an advance directive and have the physician use that as a basis for determining what orders need to be written.

In the case of a patient without medical decision-making capacity and no advance directive, the surrogate decision maker can and should work with the physician to assist in determining the course of treatment the patient would or would not want. Documenting this in a physician's order makes the patient's wishes (as expressed by the surrogate decision maker, and with the assistance of the physician) known to the patient's or resident's health care providers.

Nursing facilities will not be cited for honoring a valid DNR order which has transferred with a patient from an acute care hospital if: 1) the facilities policies and procedures allow for the transfer of DNR orders, and 2) there is factual information indicating that this is consistent with the patient's known wishes, or their best interests if their wishes are unknown.

If you have any questions regarding this letter, please contact Carol Gallegos, of my staff, at (916) 323-5761.


Margaret DeBow
Deputy Director

PHYSICIAN DOCUMENTATION OF PREFERRED INTENSITY OF TREATMENT

(Patients and surrogates should not be asked to fill out or sign this documentation of preferred intensity of treatment.)

I, _____, hereby attest that _____
(PHYSICIAN'S NAME) (PATIENT'S NAME)

has been my patient of record since _____
(DATE)

1. I have discussed the pertinent diagnoses and prognoses (documented below under #6) of the above-named patient with the patient on _____ and/or with the patient's surrogate(s)* as indicated below:
(DATE)

Name

Relationship

Date

SAMPLE

*Individuals who may have legal authority to consent to health care for an incompetent patient include an attorney-in-fact designated in a valid durable power of attorney for health care or a court-appointed guardian or conservator. In the absence of such formally named representatives, surrogates may include family members, significant others, and close friends.

2. In my judgment, the above-named patient now (does / does not) have the mental capacity to understand the nature and consequences of his/her diagnoses and the treatment options discussed here.

3. I have reviewed copies of the documents checked below (to be placed in patient's chart if available):

Durable Power of Attorney for Health Care: _____
(NAME OF ATTORNEY-IN-FACT) (DATED)

Natural Death Act Declaration: _____
(DATED)

Certified letters of guardianship or conservatorship: _____
(NAME OF GUARDIAN OR CONSERVATOR) (DATED)

Court orders: _____
(NAME OF JUDGE) (DATED)

Prior documentation of preferences by a physician: _____
(NAME OF PHYSICIAN) (SETTING) (DATED)

Other: _____

4. The patient (has/ has not) orally expressed to me his/her values and preferences concerning the goals and intensity of treatment. In the absence of the patient's personal directives to me, the following individual has stated the preferences of the patient and/or that individual concerning the goals and intensity of treatment:

Name: _____ Relationship: _____

5. The documents and discussions indicated above reflect the following preferences concerning the goals and intensity of treatment:

6. The following medical conditions are pertinent to the intensity of treatment determinations indicated below:

7. Based on the above discussions and/or documentation, the overall goal of treatment of the above-named patient is to be (check one):

- restorative (attempt to cure)
- supportive (maintain current level of function)
- palliative (provide only comfort care)

SAMPLE

(If a palliative care approach is chosen, the primary goals of treatment will be to reduce suffering, promote comfort, and preserve dignity, with the understanding that these goals may require flexibility -- e.g. hospitalization for symptom control, or use of antibiotics for an infection that is uncomfortable but not life-threatening.)

8. Consistent with the overall goal of treatment stated above, intensity of treatment should be as follows:

THERAPY/INTERVENTION	YES	NO	CALL M.D.*
CPR**	<input type="checkbox"/>	<input type="checkbox"/>	
Hospitalization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intravenous fluids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medically provided nutrition via nasogastric or gastrostomy tube	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Antibiotics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	

Further comments or clarifications: _____

* "Call M.D." acknowledges current uncertainty regarding intervention; decision is to be made as the relevant situation arises.
 **For the purposes of this form, unless otherwise specified, "No CPR" indicates no cardiac compressions, defibrillation, intubation, mechanical ventilation, ACLS medications, or vasopressors.

Physician's signature: _____ Date: _____

The purpose of this form is to help document the physician-patient decision-making process with regard to life-sustaining treatments. Information contained herein is presumed to remain valid indefinitely; however, it is expected that the patient's condition will be reviewed periodically and that the physician will amend or rewrite the form if new data become pertinent.

Use of this form is not required by law in nursing facilities, but facilities are subject to citation if they withhold such treatments without adequate documentation. The physician has a professional obligation to address end-of-life decision-making, to inform and guide this decision-making process, and to document this process in the nursing facility chart. Patients and family members should not be asked to choose from a list of treatment options without medical guidance. In particular, the poor outcomes of CPR in frail nursing facility residents should be made known.

"No CPR" must be written as an order. The "No CPR" order does not require that the patient or surrogate sign any form. (The Emergency Medical Services Pre-Hospital DNR Form, which is potentially useful during EMS transfers, does require patient or surrogate signature.)