

May 1, 2002

PROCESS GUIDELINE FOR END-OF-LIFE CARE

CARE STEP PROCESS	EXPECTATIONS	RATIONALE
Assessment and Problem Recognition		
1. Did the facility identify the impact or implications of an acute illness or current condition for the resident's long-term prognosis (outlook)?	We expect you to communicate with a physician or physician extender and expect that either they or another appropriate individual (i.e., someone who understands and can interpret medical issues) explains a resident's general condition and prognosis to the resident or an appropriate substitute decision-maker, sometime within the first month after a long-term admission or as indicated for a short-term admission. This should be done sooner if decisions to withhold or withdraw life-sustaining intervention may have already been made or may need to be made promptly for someone with a terminal or advanced or advanced end-stage condition.	The resident or an appropriate decision-maker has the "right" to receive health-related information. This information assists with "informed-decision making."
2. Did the facility identify and collect documents and other information related to advance care planning (advance directives, other written instructions, etc.) that was relevant to carrying out the resident's wishes related to end-of-life care?	We expect you to ask the resident or family about the existence of any documents related to advance care planning, such as durable power of attorney, and about any decisions, such as Do Not Resuscitate (DNR), that may have been made during a recent hospitalization. We recognize that sometimes it is difficult to get families to provide requested documents. In such cases, we expect you to document that you tried to get them. When you are able to obtain relevant documents, we expect you to show that you reviewed and tried to clarify the information in those documents as necessary and that you used that information to guide your presentations to a resident or substitute decision-maker about end-of-life options. We expect	Ending curative or rehabilitative care is a very difficult decision for any person, family, patient advocate or guardian. Unless a person expresses preferences about health care treatment and communicates those choices, through written advance directives or conversation, others may be forced to make the choices.

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	<p>you to identify, in conjunction with the attending physician, whether qualifying conditions such as a progressive irreversible or terminal condition exists. If an advance directive states that someone would not want cardiopulmonary resuscitation (CPR) instituted or only wanted life-sustaining treatments that would help improve or stabilize their progressive irreversible or terminal condition, their wishes must be honored.</p>	
<p>3. Did the facility determine and document an individual's decision-making capacity appropriately?</p>	<p>We expect you to choose and use a consistent approach to determining decision-making capacity. We expect you to be able to show how you determined that someone had partial or no decision-making capacity.</p>	<p>Determination of decision-making capacity is relevant to many other issues. Each resident should be involved as much as possible in advance care planning and decisions affecting their treatment choices, depending on their decision-making capacity. Individuals who lack significant decision-making capacity may still be able at least to express preferences effectively. But decision-making capacity is not the same as legal competence and is affected by--but not equivalent to--cognitive function.</p>
<p>4. Did the facility hold and document conversations or meetings with the appropriate decision maker regarding end-of-life issues?</p>	<p>The social worker is usually responsible for discussing and obtaining the appropriate documents related to end-of-life issues in long term care. There should be documentation that this conversation has taken place in the social workers or physician notes.</p>	<p>Documentation will serve as <u>legal proof</u> that a "good-faith" effort has been made to inform the resident/substitute decision maker of the resident's health status, and to obtain documentation relevant to this issue.</p>

<p>5. Did the facility identify factors influencing the individual's decision-making capacity?</p>	<p>We expect you to show that you have considered at least common possible causes of impaired cognition or level of consciousness including adverse drug reactions, fluid and electrolyte imbalance, and hypo-or hyperthyroidism. We expect you to explain reasons for not addressing a potentially treatable cause of impaired decision-making capacity or for not considering such factors in determining or reconsidering an individual's decision-making capacity. For instance, if a family member was making choices for a resident who had delirium and that resident's decision-making capacity improves when the delirium resolves, then we expect you to reassess the resident's decision-making capacity and review decisions that were made regarding end-of-life care previously by someone else, or explain why doing so was not indicated.</p>	<p>Sometimes, decision-making capacity can be improved by addressing correctable underlying factors such as fluid and electrolyte imbalance or other medical conditions or medication side effects.</p>
<p>6. Did the facility inform the resident of the right to make decisions on his/her care <u>or</u> inform an appropriate substitute decision-maker of the right to make decisions on behalf of an incapacitated individual?</p>	<p>We expect you to show that you have complied with relevant state and federal requirements related to informing people of their rights to make decisions and to refuse treatment. When someone is incapable of making decisions, we expect you to have selected and informed an appropriate substitute decision-maker of the right to do so on behalf of the incapacitated individual. We expect you to have an organized approach to identifying an appropriate primary or substitute decision-maker, consistent with state law and regulations. We expect you to be able to explain how you determined that you were obtaining decisions about care from the appropriate individual. We recognize that it is not always possible to find or communicate effectively with individuals who might be needed for such discussions or decisions. In such cases, we expect you to be able to show that you have</p>	<p>The "right" to make decisions regarding treatment is a state and federal regulation. The substitute decision-maker retains that "right" on behalf of a resident with impaired decision-making capacity. During the "survey process" the selection of the substitute decision maker will not be questioned. It will be assumed that you have utilized an "organized approach" in the selection of that individual. In the case where the selection of the substitute decision maker becomes a "controversial issue" it is best to go through legal channels to make such a determination.</p>

made a good-faith effort to make such contacts, and to explain why you concluded that a given individual could not or would not participate effectively. Where several different individuals contend for the role as primary decision-maker, you should follow relevant legal requirements for determining succession. For instance, you should not bypass the resident and take decisions from someone else in situations where the resident has decision-making capacity, unless you have a legally and medically valid reason for doing so. We do not expect you to try to satisfy or communicate equally with all such individuals who claim a stake in the decision-making process. We recognize that such situations are not clear and can be complicated by family dynamics. Nevertheless, we expect that deviations from a consistent approach will be exceptions, not the rule. Sometimes, a resident will lack decision-making capacity and there will be no effective input from either the resident or a substitute decision-maker, then we expect you to document why such decisions were in the resident's best interests and were relevant to their condition and prognosis.

Treatment/Problem Management

7. Does the facility have and consistently apply policies supporting the offering of alternative approaches for end-of-life care or notify residents and families of significant limitations to their choices?

We expect you to inform your staff and practitioners about commonly accepted alternatives for end-of-life care; for example, principles of palliative care, hospice care, and the recognition that artificial nutrition and hydration can be ethically and medically inadvisable in certain situations. We expect you to have policies and procedure that promote offering relevant options for end-of-life situations, or to advise residents and families **prior** to admission that the facility does not wish to facilitate the selection of certain options; for example, does not wish to care for individuals who

Terminology related to commonly accepted alternatives for end-of-life care (i.e. palliative care, hospice care, comfort care) could be confusing for staff. It is important to educate facility staff regarding the "meaning" the facility attaches to this terminology. An end-of-life policy and procedure will also serve to clarify facility intent. The facility has an obligation to inform families of

	<p>refuse intravenous fluids or tube feedings if they stop eating or drinking because of a progressive irreversible condition.</p>	<p>end-of-life options that are not supported by its' policy and procedures prior to admission.</p>
<p>8. Did the facility present relevant treatment or management options to a resident or substitute decision-maker?</p>	<p>We expect you to show how decisions about rendering or withholding treatments -- PR, hospital transfers, artificial nutrition and hydration, etc. -- were made. Those decisions should be made with the primary decision-maker's input and considering the resident's values and wishes (where these are known), and should be guided by the attending physician's assessment of the resident's condition and prognosis (as best as can be made). We recognize that individuals will have different expectations in similar situations, based on personal and cultural differences. We expect that there may be different treatment decisions for different individuals in similar situations. We do not expect all treatment options to be presented and recognize that many treatments may be inappropriate or medically ineffective in certain individuals; for instance, the determination that an intervention would prolong pain and therefore is not in a resident's best interests or the recognition of the evidence that tube feeding does not materially prolong life in individuals with end-stage dementia or other end-stage medical conditions.</p>	<p>Some treatment options are more relevant than others. The physician, along with the primary decision-makers input will serve to make the "best" determination possible for the resident.</p>
<p>9. Did the facility's plan of care incorporate a resident's wishes regarding the extent and aggressiveness of interventions or treatments?</p>	<p>We expect you to show that the care plan and related orders have taken into account the patient's values and wishes regarding treatment options. For example, if the patient said they did not want to be resuscitated or did not want mechanical ventilation, then we expect either that the medical orders reflect those wishes or that you document why an alternative approach was deemed appropriate despite those wishes; for example, CPR may be deemed medically ineffective in a terminally ill individual despite the family's insistence</p>	<p>The advanced directive together with the advanced care plan increases the likelihood that the resident's wishes would be followed.</p>

<p>10. Did the facility identify the specific elements to be given or withheld as part of a palliative care or “comfort care” plan?</p>	<p>that it be provided.</p> <p>We expect you to explain why you decided to offer or not offer specific treatment options for individuals in end-of-life situations. For example, if a situation such as weight loss or declining condition arises and the physician determines that treatment options such as nutritional supplements or additional fluids would not change the outcome, we expect you to document the basis for such a conclusion briefly in the medical record. For example, explain briefly why the individual’s condition or prognosis makes weight stabilization or fluid and electrolyte balance unachievable or undesirable. When treatment recommendations or substitute decision-maker expectations differ markedly from a resident’s express wishes or advance directives, we expect you to refer the case to an ethics advisory committee or review it with the medical director to try to resolve disagreements and identify actions that are in the resident’s best interests.</p>	<p>The physician is trained to analyze the efficacy of treatments in relation to expected outcomes. At end-of-life there is and delicate balance to be achieved between life-sustaining treatments and palliative care.</p>
<p>11. Did the facility implement a palliative care plan consistently including relevant orders?</p>	<p>Terms such as “palliative” or “comfort” care don’t always mean the same to everyone who uses them. Additionally, there are times when specific medical treatments may be provided as a palliative measure; for example, diuretics may improve respiratory comfort in someone with end-stage heart disease. So, we expect you to identify the key components of palliative care in your facility including things that are or are not to be rendered. If you have identified the general elements of palliative care, then it may be appropriate to simply institute a “palliative care protocol” as indicated. We expect you to clarify significant elements of a care plan that deviate from the general protocol; for instance, palliative care except for oral antibiotics for an acute infection.</p>	<p>Key aspects of palliative care include: meticulous symptom control; psychosocial and spiritual care; and a personal management plan that maximizes resident determined quality of life. (Valente, S.M. <u>End-of-Life Issues</u>. Geriatric Nursing 2001. Vol. 22.(No.6).</p>

Monitoring

<p>12. Did the facility review the plan related to end-of- life care with residents or substitute decision-maker when a significant condition change occurred?</p>	<p>We recognize that circumstances may change and that people may change their minds about prior treatment choices. We expect you to periodically review the overall plan for a resident’s end-of-life care with a resident or substitute decision-maker, or to indicate that they were unavailable when you tried to do so. We expect at least an annual review, or one as indicated when there is a new, serious condition change that is likely to be permanent, such as when an individual has had multiple recent hospitalizations or recurrent acute illnesses that may represent an overall decline or evolving end-of-life situation.</p>	<p>At end-of-life, a deterioration of condition can be expected. Periodic monitoring of the plan of care, and ongoing communication with the resident and/or the substitute decision maker regarding their concerns/wishes is necessary.</p>
<p>13. Did the facility modify the resident’s care plan to reflect changes in decisions by the resident or a substitute decision maker?</p>	<p>We recognize that circumstances may change and that people may change their minds about prior treatment choices. We expect you to periodically review the overall plan for residents end of life care with the resident or substitute decision maker, and remain “flexible” regarding requested changes.</p>	