SELF DETERMINED LIFE CLOSURE

FAQ’s

1. If the patient wants CPR but family and staff believe it will be futile what do I do?
   Monitor the patient’s condition. Often as patients approach their death they change their minds. It is not necessary to bring this up on every visit; clinical judgment is involved. The measure is not intended to be more important than the person.

2. What is a hospitalization for a hospice patient?
   The term “hospitalization” has meanings for patients that may not coincide precisely with providers’ traditional definitions of hospitalizations. The Medicare Hospice Benefit “general inpatient” regulation similarly expands the concept. For example, “is admission to a SNF under general inpatient care a hospitalization?” Technically, no. Nursing homes are not licensed as hospitals. But if patients are sent to SNF’s to receive higher level (general inpatient) care than that available at home or at the skilled level, and that care is similar to the care the same patient could receive in a hospital, it is reasonable to consider it a hospitalization.

Interpretations are even more complex when considering a patient’s perspective. Patients and families will advise hospice staff that they look forward to spending time in the special inpatient environments created by the hospice, even as they state they want to avoid hospitalization. We have learned it is not the mere fact of being transferred out of the home that is of concern to many patients, but where and what they are being transferred to. Patients are often fearful that the wrong thing will happen to them in hospitals where the care is not tailored to the needs of a dying dependent patient. Prominent national studies tell us that their fears are realistic. If dying is the ultimate “experience,” it is important to pay attention to the circumstances that contribute to the best experience, regardless of necessary setting.

Patient Driven Definition. “Avoiding hospitalization” is a theme in many consumer surveys regarding end of life care. Looking more specifically at what consumers fear will happen, the following issues are identified:

1) Loss of control,
2) Loss of identity,
3) Fear that treatments will be performed against their will,
4) Inability to have significant others around,
5) Fear that responses to toileting problems will not be addressed in a timely or dignified way,
6) Fear that symptoms will not be effectively managed; “hospitals are geared toward cure, not comfort.” And for some,
7) Fear of acquiring hospital bred infections
A Philosophy of Care Regardless of Setting. Patients who have signed an informed consent for hospice care are to receive that care regardless of the care setting, until they notify their physician of a change in preference. Consequently, hospices are expected to work with staff in acute and skilled care settings to insure that patients’ preferences are met, that they will neither be isolated nor abandoned to their illness, that their special communication needs will be facilitated and that symptoms will be effectively addressed. The goal is for the care delivery to appear seamless when a change in setting is necessary. The greatest opportunity for this to happen is when staff from the hospice and inpatient setting work collaboratively. Joint care planning, shared documentation and daily communications contribute to the success of this effort. When the items identified above are offset by such collaborative team efforts it is reasonable to say that the hospice has taken responsibility to help patients avoid what they fear: what hospitalization represents, not its bricks, mortar or license.

Implications for Dataset. Every hospice that fills out the dataset sheet on the hospitalization measure will have to ask itself a number of questions regarding its inpatient relationships in order to accurately reflect its ability to help patients avoid loss of control and the fearful things identified above. It was the opinion of the expert panel of the Outcomes Forum to not just focus on the licensure of the inpatient care setting in asking the hospitalization question, but to look at what lies behind the question. That means that all transfer sites need to be evaluated in their potential to help the hospice team provide the care that the patient anticipates.

That means, if it is not possible to substantially direct and influence the care of patients the hospice should designate all transfers from home to that facility as a hospitalization. If collaboration between settings is high, and “the bricks disappear,” such a transfer is not counted as a hospitalization. The specific criteria for collaboration follow, with examples of what is and is not a hospitalization.

In summary, this is acknowledged to be a variant view of “hospitalization.” Its definition is driven by patient perception and expert knowledge of patients’ concerns, not by the mere fact of contractual relationships and licenses. Those who are interested in determining how hospices vary in keeping patients at home are encouraged to look at the hospice’s % of patient days spent in routine home care, compared to hospices of similar (budgetary, geographic, bed availability) profiles.
## Types of inpatient settings

<table>
<thead>
<tr>
<th>Is this a hospitalization?</th>
<th>YES</th>
<th>NO</th>
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<tbody>
<tr>
<td>Admission to a hospital or SNF where all of the following apply: 1) Hospice staff communicate with hospital staff or patient/family <strong>daily</strong>; 2) Treatment care plan is jointly derived; 3) Hospice staff document in hospital's medical record 4) The hospice monitors the quality of care provided to hospice patients in the hospital</td>
<td>X</td>
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<tr>
<td>Admission to a hospital or SNF* where any of the following apply: 1) Hospice staff do not communicate with hospital staff or patient/family <strong>daily</strong>; 2) Treatment care plan is not jointly derived; 3) Hospice staff cannot document in hospital's medical record 4) The hospice does not monitor the quality of care provided in the inpatient setting</td>
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<td>X</td>
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<td>Discharge to a non-contract SNF</td>
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<td>Admission to a freestanding hospice inpatient facility for general inpatient care</td>
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<td>X</td>
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<tr>
<td>Admission to an inpatient unit in a hospital or SNF that is managed by the hospice</td>
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<td>X</td>
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* Patients may receive “general inpatient care” in some SNFs, as they do in hospitals.