

## Palliative Care

There is a disparity between the ways in which people die in the United States and the way in which they want to die. The recent shift toward permitting residents to die within nursing facilities has been difficult for some nursing facility staff. Nursing facilities have long attempted to keep the numbers of nursing facility deaths low, and many nursing facilities lack clarity about whether and how to care for the end of life resident.

The Midwest Bioethics Center to improve end-of-life care stated in their December 1999 "Focus on Long Term Care" part one series that about one-third of Americans will receive care in a nursing facility before they die, and the average stay is four years. About one-fifth of Americans will die in a nursing facility. Long Term Care facilities have become a focus in improving end of life care/palliative care.

Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without affecting a cure. In a broad sense it *is not restricted to those who are dying or those enrolled in hospice programs*. It attends closely to the emotional, spiritual, and practical needs and goals of residents and those close to them. The World Health Organization defines end of life care/palliative care as the active total care of patients whose disease is not responsive to curative treatment.

Control of pain, other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of care is achievement of the best quality of life for patients and their families. With this in mind, implement the assessment of pain as the 5<sup>th</sup> vital sign, clinicians should be continually assessing. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment.

Good palliative care is dependent upon the skills and attitudes of all those who treat and support residents at the end of life. Education of nursing facility staff, physicians, regulators and families of residents is necessary in the area of end of life care. The best practices focus on providing educational information regarding the coordination of hospice benefits when it is appropriate in the nursing facility, in care planning, and in the whole patient assessment.

## Hospice Services in the Nursing Facility

Medicare Part A Hospice benefits provides palliative care to individuals who are certified terminally ill (a medical prognosis of a life expectancy of 6 months or less if the illness runs its normal course). Hospice palliative care focuses on pain control, symptom management, and counseling for both the patient and family. A beneficiary who elects to enroll in a hospice waives his or her rights to all curative care related to his or her terminal illness. Medicare will continue to pay for services furnished by the patient's non-hospice attending physician and for the treatment of conditions unrelated to the terminal illness.

### Services

The hospice must have a written plan of care, which covers physician and nursing services; physical, occupational and speech therapy; medical social services; home health aides and homemakers; short term inpatient care; counseling; respite care; and medical supplies, including drugs and biologicals. Certain of the hospice "core" services must be provided directly to the beneficiary by the employees of the hospice, while other non-core hospice services may be provided in accordance with other providers. However, the hospice must retain professional management for all contracted services.

### Reimbursement

For services provided to patients in nursing facilities, hospices receive the Medicare routine home care rate, which is a fixed amount per day for the services provided by the hospice, regardless of the volume or intensity of the services provided. Accordingly, where the hospice patient resides in a nursing facility, the patient/secondary payor source remains responsible for payment of the nursing facility's room and board charges.

If, however, resident's receiving Medicare hospice benefits in a nursing facility are also eligible for Medicaid, Medicaid will pay the hospice at least 95% of the states daily nursing facility resident's TILE rate. The hospice is then responsible for paying the nursing facility for the hospice resident's room and board rate.

In addition to the room and board payment, a hospice may contract with the nursing facility for the nursing facility to provide non-core hospice services to its hospice patients.

## End of Life - Whole Patient Assessment

A patient assessment in end of life care differs from other clinical assessments in that its goal is to permit the relief of suffering. The goal is to care for the whole resident not just the disease. The whole patient assessment should start with the taking of a good history. Begin with:

<p><u>Illness/treatment summary</u></p> <p>A resident near the end of life will likely have a long medical history with multiple interventions. Ask if the treatments cause any adverse effects.</p>
<p><u>Physical Assessment</u></p> <p>It is best to organize the assessment by symptoms and functional activities rather than by organ system or anatomy. After symptoms and physical impairments are assessed, then conduct a physical examination/assessment.</p>
<p><u>Common Symptoms</u></p> <p>The most common symptoms at the last phase of life is pain, weakness/fatigue, breathlessness, insomnia, wt. loss, confusion, constipation, anxiety, nausea/vomiting, and depression. Ask the resident about each one. Each symptom should be thoroughly assessed to help determine when the symptom began and to determine the potential cause or causes. Psychological, social, and spiritual factors may play a strong role in the development of physical symptoms.</p>
<p><u>Pain &amp; Severity</u></p> <p>Pain is present in up to 90% of residents with cancer and AIDS. Pain is highly prevalent in the last phase of life and often under treated. There is no reliable way to assess what the patient is experiencing other than by asking them. To manage the pain and gain a clearer understanding, it is important to ask specific questions to elicit the information. See the attached two forms to assist the staff licensed and non-licensed in reporting symptoms of pain.</p>
<p><u>Function</u></p> <p>Assess both motor and sensory functions.</p> <ul style="list-style-type: none"><li>↳ Can the resident move around?</li><li>↳ Can the resident see or hear well enough?</li><li>↳ Can the resident complete activities of daily living?</li><li>↳ How are the physical aspects of relationships including sexual function?</li></ul>
<p><u>Psychological Assessment</u></p> <p>First assess resident's cognition. Among the most important psychological issues is to assess what the residents understanding is regarding the illness, what is there emotional state, their level of communication and support, and the existence of any unresolved issues. It is important to assess whether the resident is coping adequately or should the attending physician be notified for a referral. Do not hesitate to ask screening questions about suicidal ideations. Ask about mood, anxiety, sadness, and depression. Refer to Depression Best Practice for tools to assist with assessing for signs of depression.</p>

### Emotional Responses to Illness

Assess resident's emotional response to the illness. Ask about how the resident is responding to the fact of being ill. Considering naming some common responses, such as anger, grief, instability, and tranquility. Inquire about his or her emotions, and then actively listen to the resident's responses. Then acknowledge the emotions in an accepting way.

### Fears

In tailoring a plan of care, it is critical to know what it is that the resident tends to fear, such as fear over loss of control, loss of dignity, loss of relationships, physical suffering and issues related to financial economic areas.

### Unresolved Issues

Unresolved issues in personal matters and especially in relationships are a prominent part of the experience of residents at the end of life. You may discover that what stands between the resident and a comfortable frame of mind is an unresolved issue. Questions that can directed to this area are:

- ↪ Is there something that you would like to do before you get too sick?
- ↪ Is there anyone you want to be able to communicate with before you die?
- ↪ Many people have places or people they would like to visit. Do you?
- ↪ Some have a piece of work they would like to finish. Do you?
- ↪ In what ways has this illness affected you emotionally?
- ↪ Are you doing things that you enjoy?
- ↪ How has your mood been lately?
- ↪ How have you been coping with all of this?
- ↪ How have you handled stress in your life?
- ↪ Are you concerned about being a burden to others?
- ↪ Do you feel in control of your life right now?

### Communication assessment

Determine whether the resident is a "talker" or a "silent type". As part of routine interaction with the resident, ask if the resident understands what is being said and if he or she has answers to all his or her medical questions. Ask the resident if he or she wants a lot of information or not so much. Ask how he or she wants to involve family and friends in information about the illness. Be particularly attuned for difficulties if the resident is keeping his or her diagnosis a secret, or if the family is doing the same in reverse.

### Spiritual assessment

Spiritual life is understood by some in terms of religious feeling and by other in terms of personal meaning in a larger context. Find the interpretation most fitting to the resident. Determine whether or not he or she would like a pastor to visit and whether there are religious/cultural rituals (special prayers or actions, last rites, etc.) that are important.

## Goal of Care

Goals of care with residents and families who are facing the end of the resident's life can be difficult, particularly when there is a conflict between aspirations and what is medically likely or possible. The attending physician should have already clarified the

current situation with the resident and their family in which decisions were made in determining the context of the goals of care. Some goals may be contradictory, such as the resident may want prolongation of life as the overriding goal but also insist that nothing should be done (e.g. chemotherapy); that increases discomfort. As the residents health status worsens, the goals of prevention, cure, or avoidance of death may become less important as they become less possible. At the same time, the goals of maintaining function, relieving suffering and optimizing quality of life may become the focus of care.

## Pain Assessment Questions

<b><u>Location</u></b> <ul style="list-style-type: none"><li>↵ Where does it hurt most?</li><li>↵ Does the pain go anywhere?</li><li>↵ How does your pain change over time?</li><li>↵ How long have you had this pain?</li><li>↵ Did it begin gradually or all of a sudden?</li><li>↵ Does it come and go, or do you have it all the time?</li></ul>
<b><u>Quality</u></b> <ul style="list-style-type: none"><li>↵ What words might you use to describe the pain?</li></ul>
<b><u>Severity</u></b> <ul style="list-style-type: none"><li>↵ How bad is it on average?</li><li>↵ How bad at its worst?</li><li>↵ Is it progressing or remaining stable?</li></ul>
<b><u>Modifying factors</u></b> <ul style="list-style-type: none"><li>↵ Does it feel better when you're in a certain position?</li><li>↵ Do you notice any change with various activities?</li></ul>
<b><u>Impact on function</u></b> <ul style="list-style-type: none"><li>↵ To what extent does the pain interfere with your normal activities?</li><li>↵ What about your sleep?</li><li>↵ Your ability to walk?</li><li>↵ Your relationship with others?</li></ul>
<b><u>Effect of treatments</u></b> <ul style="list-style-type: none"><li>↵ What have you been doing for the pain?</li><li>↵ Have you taken any medications?</li><li>↵ How much relief does that provide?</li></ul>
<b><u>Resident perspectives</u></b> <ul style="list-style-type: none"><li>↵ What do you think is causing the pain?</li><li>↵ What does the pain mean to you?</li><li>↵ Would you like me to notify you physician, to ask about prescribing something?</li></ul>

Pain assessment in the cognitively impaired person, such as an elderly resident with dementia, is challenging. Behaviors such as grimacing, moaning, crying, agitation, or changes in appetite may be the only way to assess pain.