Beloit Regional Hospice

Supporting the Spirit of Life

A publication for physicians and other health care providers

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At Beloit Regional Hospice, our mission is to help make each moment of remaining life as full and comfortable as possible.

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Hospice Levels of Care

Periodically questions arise regarding the levels of care provided for hospice patients. The Medicare Hospice Benefit provides for comprehensive care that includes four levels of care:

- Routine Home Care
- Continuous Home Care
- Inpatient Respite Care
- General Inpatient Care

The choice of the level of care is based on the symptom management needs at the time of admission and as the patient's needs evolve. The primary physician and the hospice team will communicate with the family and the patient about changes in the patient's needs. The Beloit Regional Hospice team will make a recommendation based on their assessment of the patient and work collaboratively with the primary care physician.

Routine Home Care is basic care provided by hospice in the place the patient calls home. This may be a private residence, an assisted living facility, or a long term care facility. The majority of hospice patients are cared for with routine home care by the Interdisciplinary Team.

Continuous Care is offered only on a short-term basis in the case of a crisis situation or when acute medical symptoms arise (that are conducive to treatment in the home setting). During continuous care the patient would receive primarily nursing care for a minimum of 8 hours up to a full 24 hours of care. Indications for continuous care would include severe pain, severe respiratory distress, uncontrolled symptoms, imminent death with severe symptom issues, or concern about suicide. Several factors are considered in the decision(s) to use continuous care instead of general inpatient care: the patient wishes to stay at home, moving to another setting would cause hardship, or more effective symptom management can be achieved in the home setting. Stringent regulatory requirements make continuous care difficult to justify, and sporadic need creates staffing challenges. The combined result is limited use of this level of care.

Inpatient Respite Care is provided when it becomes necessary to give relief to the caregiver or when it is required that the patient be removed from the home for a short period. Respite care, limited to 5 days or less per episode, is provided in a contracted facility, a hospice residence, or inpatient unit. The hospice plan of care remains in place during the respite stay.

General Inpatient Care is indicated when pain or other acute symptoms cannot be managed in the residential setting. GIP must be provided in a contracted hospital or skilled nursing facility that meets the requirements for 24-hour nursing. There is a cap placed on this care for Medicare patients. The total number of inpatient days (including respite or GIP) may not exceed 20% of the total Medicare days billed for the same time period. The plan of care must also reflect the specific symptoms requiring intervention in an inpatient setting, and the scope and frequency of services required.

All hospice patients are entitled to receive the most appropriate level of care for their current condition and symptoms. Accommodating their changing needs requires collaboration and communication across the Interdisciplinary Team and with the involved physician and facility staff. As always, the staff at Beloit Regional Hospice is ready and available to answer questions and to work closely with you to meet the needs of your patients. Please contact us at 608-363-7421.

Palliative Sedation: Ethically and Methodologically Different from Euthanasia and Assisted Death

Majority of neurologists surveyed endorse this "acceptable therapeutic option," while NHPCO addresses issues and protocols

The overwhelming majority of neurologists responding to an ethics survey agree that the purpose of palliative sedation — referred to as "sedation for the imminently dying" (SFTID) — is to relieve suffering, and is neither morally nor legally equivalent to euthanasia.

That is according to a report published in *Neurology,* the official scientific journal of the American Academy of Neurology, whose Ethics Section conducted the survey.

"Sedation for the imminently dying is a palliative care method that is available and supported by published guidelines," write the authors. "Sedation for the imminently dying is administered with the intent of relieving symptoms — not hastening death."

The responses of 111 neurologists with a self-identified interest in ethics (male, 69.5%; U.S. resident, 91%) were analyzed to determine their familiarity and experience with, and attitudes toward, SFTID.

The term SFTID was chosen for the purposes of the survey as being both more explicit than the commonly used "palliative sedation," and less cumbersome than the descriptive "continuous deep sedation for patients nearing death." In addition, "terminal sedation" was rejected as misleading, erroneously suggesting that the intent is to terminate life. "Imminently dying" refers to those patients expected to die within a span of days to a few weeks.

Key Findings Include:

- 96% of respondents agreed or strongly agreed that the primary purpose of SFTID was to relieve suffering.
- Most disagreed or strongly disagreed that SFTID was morally (83%) or legally (85%) equivalent to euthanasia.
- 92% agreed or strongly agreed that SFTID was acceptable for patients with metastatic cancer who were nearing death.
- 58% indicated they would consider prescribing SFTID with the support of an institutional policy, while 38% would be willing to proceed regardless of policy.
- Only 0.9% of respondents stated they would never prescribe SFTID.

"SFTID is controversial because of the perception that administration of sedation to imminently dying patients is equivalent to euthanasia, thus making many health care professionals and members of the public uncomfortable with the concept," the authors point out.

Methodologically, SFTID differs significantly from euthanasia in the following ways:

- The administration of SFTID is titrated and proportionate.
- It requires frequent monitoring and documentation of patient response.
- SFTID uses drugs that are predominantly sedative in nature (rather than narcotic or paralytic).

"Numerous research studies and reviews show that when properly and proportionately applied under monitored conditions, SFTID does not accelerate the dying process," comment the authors. "Patients who receive SFTID die of their terminal illness and not from the administration of SFTID."

NHPCO Statement and Commentary on Palliative Sedation

The National Hospice and Palliative Care Organization (NHPCO) has released a position statement clarifying its position on the use of palliative sedation, recommending is-

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NHPCO Statement on Palliative Sedation: Core Tenets

- **Availability:** The option of palliative sedation, delivered by highly trained health care professionals within an interdisciplinary team, should be made available for the small number of imminently dying patients whose suffering is intolerable and refractory.
- **Proportionality**: Sedation should be titrated to reduce consciousness to the minimum level necessary to render symptoms tolerable.
- **Interdisciplinary evaluation**: The intervention must be led by a physician with expertise in palliative care. Involvement of a highly-skilled interdisciplinary team, interdisciplinary conferences for each individual patient, and a focus on patient-and-family-centered care are all strongly recommended.
- **Education**: Training, competence, and ongoing education in providing palliative sedation — as well as the ability to integrate ethical considerations — are essential for all professionals involved in the delivery of this intervention.
- **Concerning Existential Suffering**: Although lack of concurrence by its ethics committee precludes a recommendation regarding palliative sedation for existential suffering, the NHPCO stresses the importance of the ethical obligation held by palliative care professionals to address this form of suffering, using the knowledge, tools, and expertise of the interdisciplinary team.
- **Relationship to Euthanasia and Assisted Suicide**: Palliative sedation is categorically distinct from euthanasia and assisted suicide. Properly administered, palliative sedation of patients who are imminently dying is not the proximate cause of death, nor is death a means to achieve symptom relief.

— Adapted from Kirk and Mahon, Journal of Pain and Symptom Management

GOAL-DIRECTED INTERVENTIONS TO RELIEVE SUFFERING DEEMED PALLIATIVE 'TREATMENT'

EXPERTS PROPOSE A SHIFT IN TERMINOLOGY AND CONCEPT FROM 'PALLIATIVE CARE'

Because therapy directed by health care professionals to alleviate suffering encompasses much more than "care" — which connotes to many a benevolent watching over that requires no special skills — two California experts in bioethics and pediatrics are advocating for the use of a more accurate term, as outlined in their article published in the *Journal of Palliative Medicine*.

"Expertly directed palliative care is really treatment, and it should be called what it is: 'palliative treatment,'" write Alexander A. Kon, MD, of the University of California, Davis, and Arthur R. Ablin, MD, University of California, San Francisco. "[T]his shift in our conception of the treatment of suffering from 'care' to 'treatment' is necessary, so that palliative treatment receives its proper recognition in our medical armamentarium."

According to the authors, palliation of suffering is treatment because it is evidence based, goal directed, and effective in reducing suffering. "Labeling evidence-based, goal-directed interventions that ameliorate suffering as treatment rather than as care represents an important conceptual shift and is not merely a semantic alteration," the authors maintain. In addition, the change in terminology may aid patients in their decision making.

Presenting terminally ill patients with a choice of pursuing either aggressive "treatment" in an attempt to prolong their lives, or of switching the focus to palliative "care" to actively relieve their symptoms can be misleading, note the authors. Patients may believe that treatment — of any type — is the more desirable option, and that by selecting the passive-sounding "care," they are no longer pursuing any goals and are "giving up."

PHYSICIANS CAN USE THE TERM 'PALLIATIVE TREATMENT' TO HELP PATIENTS UNDERSTAND THAT:

- The goals of treatment will be redirected, using the best possible medical knowledge and expertise.
- Because palliative treatments are goal directed, patients can still maintain hope — for the relief of a symptom, for instance — without feeling they are giving up.
- Although the treatment of suffering may not eliminate all symptoms, their providers will use the same active approach they would for any other treatment.

ADDRESSING SUFFERING

"Palliative treatment is the treatment of suffering; it is therefore imperative that we recognize all forms of suffering in order to fully treat patients," the authors write. Physical suffering is now often recognized, assessed, and treated, and interventions for physical symptoms can be quite successful. The same cannot be said, however, for psychological, existential, and spiritual suffering, which can oftentimes go unnoticed and unchecked.

These other forms of suffering can sometimes be even more burdensome for patients than physical suffering, and are best addressed by a multidisciplinary approach, the authors recommend. Psychologists, social workers, nurses, chaplains, and child-life therapists for children can assist in addressing not only the suffering of patients, but also the needs of their families and loved ones.

The authors also suggest that, for those patients with unbearable suffering that is uncontrolled despite the best efforts of the health care team, and for whom life itself has become a burden, allowing death to occur "unimpeded" may be a therapeutic option.

"Because the quality and quantity of suffering is necessarily subjective, there can be no third-party assessment of suffering," they write. "Only the individual can weigh the benefits and burdens of life." The authors support the withdrawal of life-prolonging measures in such cases, when it is the patient's wish, and palliative sedation for the imminently dying for whom all other measures have failed.

Source: "Palliative Treatment: Redefining Interventions to Treat Suffering Near the End of Life," Journal of Palliative Medicine; *June 2010; 13(6):643-646. Kon AA and Ablin AR; Department of Pediatrics and Program in Bioethics, University of California, Davis; Department of Pediatrics, University of California, San Francisco.*

PALLIATIVE SEDATION (FROM PAGE 2)

sues and questions to be addressed when the measure is under consideration, and offering assistance to health care organizations interested in developing policies for its use.

"We want to stress in this document that palliative sedation, like all interventions in palliative care, needs to be part of evidence-based practice," states Timothy W. Kirk, PhD, lead author of the statement, which was published in the *Journal of Pain and Symptom Management*. "There are evidence-based clinical protocols based on a growing body of research that many clinicians are not aware of, but should be. Simply turning up current pain medications is not evidence-based sedation."

Source: "Sedation for the Imminently Dying," Neurology; *April 20, 2010; 74(16):1303-1309. Russell JA, Williams MA, Drogan O; Department of Neurology, Lahey Clinic, Burlington, Massachusetts; Sandra and Malcolm Berman Brain & Spine Institute, Department of Neurology, Sinai Hospital of Baltimore, Baltimore; American Academy of Neurology, St. Paul, Minnesota. "National Hospice and Palliative Care Organization (NHPCO) Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients,"* Journal of Pain and Symptom Management; *May 2010; 39(5):914-923. Kirk TW and Mahon MM, for the Palliative Sedation Task Force of the NHPCO Ethics Committee; Department of History & Philosophy, City University of New York — York College, Jamaica, New York; School of Nursing, College of Health & Human Services, George Mason University, Fairfax, Virginia.*

Intervention to Support End-of-Life Decisions via Telephone May Improve Quality of Care and Reduce Medicare Costs

End-of-life counseling delivered telephonically to Medicare patients identified by a predictive model as most likely to be in the final year of life has been found to reduce health care costs by supporting better patient choices in the last six months of life, according to a report in *The American Journal of Managed Care*.

"Individuals nearing the end of life need support in navigating the choices available to help them maximize the quality of their remaining time," write the study authors. "The value of expenditures for aggressive care at the end of life is questionable, because higher end-of-life costs are associated with poorer quality of life in its final stages."

Researchers used a validated predictive model to identify those beneficiaries participating in a Medicare chronic care management program who were at greatest risk for death. Patients were randomized into control (n = 1630) and intervention (n = 3112) groups, with 80% of the latter receiving individualized telephone education and counseling from nurses trained in end-of-life counseling.

Key findings include:

- Adjusted costs per patient in the last six months of life averaged $1913 lower in the intervention group compared with controls.
- Overall cost savings to Medicare was $5.95 million.
- While both groups had similar rates of hospice admission, the intervention group trended toward longer lengths of stay.

The authors note, "This study shows that effective end-of-life interventions can be provided telephonically by nonphysicians and that this complementary route of support can reach more of the appropriate patients, with greater overall impact than standard care as currently provided."

They stress that in no way is the validated predictive model intended to replace clinical judgment during patient interactions. Further, all patients were advised during the telephone intervention to remain adherent to their physicians' care plan and recommended chronic care management.

Because the primary outcome of their study was restricted to cost reduction, the authors strongly urge further investigation. "It is important that future studies investigate quality-of-life measures, because the opportunity to improve the quality and dignity of death for many Medicare beneficiaries has greater value than cost-saving potential."

Source: "Impact of Predictive Model-Directed End-of-Life Counseling for Medicare Beneficiaries," The American Journal of Managed Care; *May 2010; 16(5):379-384. Hamlet KS, Hobgood A, Hamar GB, Dobbs AC, Rula EY, Pope JE; Center for Health Research, Healthways, Inc., Franklin, Tennessee.*

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Beloit Regional Hospice provides all the necessary medical and support services to manage a patient's life-limiting illness, including:

- **Caregiver education**
- **Pain and symptom management**
- **Nursing care**
- **Social and emotional support**
- **Spiritual support**
- **Respite care**
- **Grief support**
- **Physical, speech, and occupational therapy**
- **Dietary counseling**
- **Medication, equipment, and supplies necessary for management of terminal illness**