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Tagline

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LIVE — Without Pain: A Campaign for Consumer Empowerment Provided by National Hospice Organization

A new initiative introduced in March 2012 by the National Hospice and Palliative Care Organization (NHPCO), in partnership with Purdue Pharma L.P., is aimed at empowering consumers to get control of their pain.

NHPCO believes that when consumers understand pain and are aware of options and issues about pain, only then can life be pain-free. This public awareness effort focuses on separating myth from fact and educating patients and caregivers to be advocates for professional, expert pain relief. Informed consumers, states the NHPCO, have the knowledge and the language necessary to engage in meaningful discussions with physicians who are managing their care.

NHPCO president and CEO, J. Donald Schumacher, Psy.D., explains, “When someone is in pain, it can be impossible to think about anything else. Pain can make it difficult for you to work, sleep, maintain relationships with friends and loved ones, and participate in simple activities.”

Pain is complex and multi-faceted. Physical pain can lead to emotional, social, and spiritual discomfort and these, in turn, can complicate physical hurt. **With their teams of interdisciplinary professionals, hospices are in a unique position to view and respond to all the suffering surrounding end of life, not only physical pain.** “There is almost always a reason why a person is experiencing pain and in most cases physical pain can be managed,” Schumacher says.

Before consumers can be strong advocates for themselves and their loved ones, they must learn the truth about pain. Myths and misunderstandings are barriers to seeking and receiving good pain management and regaining a productive life. The “LIVE — Without Pain” campaign provides free online resources that address topics such as different kinds of pain, caring for someone in pain, talking with a doctor about pain, and managing medications. Free brochures available for download include “Managing Your Pain,” “Using Narcotics Safely,” and “When Your Child Is in Pain.” Visit www.CaringInfo.org/pain.

Talking with Your Doctor about Pain

Before discussing pain with a doctor, NHPCO recommends answering the following questions:

- How long has the pain been a problem?
- Is it a new pain or has it occurred before?
- Where is the pain located? Is it in more than one area? Which is the most troublesome?
- How severe is the pain — mild, moderate, unbearable?
- Does the pain interfere with daily activities?
- What makes the pain worse?
- Is the pain accompanied by numbness, tingling, or weakness?
- What has been done to relieve the pain?
- How does the pain feel — stabbing, dull, achy, burning, sharp?

Adapted from “Talking To Your Doctor about Pain.” CaringInfo.org



End-of-Life Care News Briefs for Patients and Families

Advanced Heart Failure Patients Deserve to Have Their Doctors Initiate Dialogues about Care Preferences

Heart failure affects hundreds of thousands of families across the nation. These families know how burdensome this disease can be, both for the patient and the caregiver. Especially during the advanced phase of the disease, the patient's symptoms often limit activities of daily living, resulting in poor quality of life.

The American Heart Association (AHA) has come out with an official statement, published in the journal *Circulation*, urging doctors to engage in shared decision-making with patients who are in the advanced stages of heart failure.

Shared decision-making means that doctors would schedule automatic annual care and goal reviews with patients to "open a dialogue," focusing on "outcomes that are most important to the patient."

By engaging in frequent, timely discussions, the doctor would have many opportunities as the disease progresses to introduce hospice and palliative care options to the patient. Open discussion of the disease with a focus on the patient's current and changing goals and preferences would ensure that both parties are communicating thoroughly and embracing the same options — a true sharing of decisions.

The AHA believes that early and continuing discussions would result in earlier referrals to hospice or palliative care programs. Although the enrollment of heart failure patients in hospice is increasing, many patients are referred late in the disease process and are denied the multiple benefits associated with hospice care.

"As the end of life is anticipated, clinicians should take responsibility for initiating the development of a

comprehensive plan for end-of-life care consistent with patient values, preferences, and goals," the AHA says.

Early Discussions of End-of-Life Care Provide Advanced Cancer Patients with the Best Support for Future Choices

Studies show that patients with life-limiting cancer who talk with their regular doctor about end-of-life care options are more likely to be able to die at home with hospice and receive care that follows their preferences.

However, researchers from several major cancer centers reported in a recent issue of *Annals of Internal Medicine* that a majority of end-of-life care discussions take place when a patient is admitted to the hospital.

When these discussions occur during a

medical crisis that lands the patient in the hospital, the discussion is initiated by a hospital-based physician and not a doctor whom the patient knows. The most meaningful end-of-life dialogues about a patient's wishes, according to the study researchers, are conducted by the doctor who is most knowledgeable about the patient's prognosis and progression of the disease thus far.

Late end-of-life discussions also prevent patients from getting the psychological support that enables them to accept their situation, grieve their losses, and grow in their relationships.

Researchers recommend that doctors initiate end-of-life conversations with patients "earlier in the disease trajectory" so patients can have an informed choice of all available options, especially hospice and palliative care, and access these options earlier in the course of their disease.

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