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The Truth about Advance Care Planning in Health Care Reform Bill

Mark M Murray, President/CEO

There has been some confusion and misinformation being peddled in the media regarding the advance care planning provision in the House’s

health care reform bill. Uninformed individuals have described this provision as a mandatory session that would dictate health care choices for older Americans. This is inaccurate and has resulted in bewilderment surrounding the value of advance care planning.

Section 1233 (pages 424-434) of the House Ways and Means Committee version of health care reform contains a new Medicare provision to allow coverage for an “Advance Care Planning Consultation.” This provision is intended to offer Medicare beneficiaries an opportunity to engage in an informed and focused conversation with their health care practitioner about advance care planning options.

This consultation would be in addition to the “Welcome to Medicare” physician consultation. This consultation, like other consultations within the Medicare system, would be voluntary and would be reimbursable under Medicare when provided no more than once every five years, or whenever a patient undergoes a qualifying event, such as a life threatening or terminal diagnosis, chronic disease diagnosis; or admission to a long-term care facility, a skilled nursing facility, or a hospice program.

Topics that are covered, during the consultation, include:

- An explanation by a physician, nurse practitioner or physician’s assistant of advance care planning, including key questions and considerations, important steps and suggested people to talk to.
- An explanation by the practitioner of advance directives, including living wills and durable powers of attorney, and their uses.
- An explanation by the practitioner of the role and responsibilities of a health care proxy.
- The provision, by the practitioner, of a list of national and state-specific resources to assist consumers and their families with advance care planning, including the national toll-free hotline, the advance care planning

clearinghouses, and State legal services organization.

- An explanation of the end-of-life services and supports available, including palliative care and hospice.

The consultation is not mandatory. No one is required to undergo the consultation. The Medicare beneficiary must request the consultation.

Discussing advance care planning before a Medicare beneficiary finds him or herself in a medical crisis will help ensure the patient gets the care that he or she wants. One of the most frequent comments from family caregivers that hospice providers hear is “Why didn’t we know about this sooner?” Hospice is just one option that would be discussed in an advance care planning consultation but this would ensure patients and family caregivers knew about it earlier.

The provision has bi-partisan support in Congress. Additionally, the 1991 Patient Self-determination Act already allows for advance care planning and stresses the importance of the patient’s wishes—so this isn’t necessarily new, it would now be more readily available to Medicare beneficiaries.

What the advance care planning consultation is NOT about...

- It’s not about limiting care;
- It’s not about hastening death;
- It’s not about having choices made for the patient; and
- It’s not about saving money.

Advance care planning does involve...

- Understanding possible future healthcare choices.
- Thinking about choices in light of what is important to an individual and their values.
- Talking about your decisions with loved ones and doctors.
- Writing down plans in Advance Directives so they will be ready if needed.

It’s important to remember that...

- Plans and advance directives can be changed as a person’s situation or wishes change.
- Advance care planning is done over time and not a single conversation.
- Planning ahead for healthcare is a gift people can give to themselves and to those they love.





Preparing for our Ugandan Guest

by Greg Gifford MD and Roberta Spencer LCSW

In some ways Uganda is quite similar to the US. It is a multiparty constitutional republic, with voting rights for all 18 and older. Its official language is English. It is mainly (84%) Christian. Its courts are based on English common law.

It is quite dissimilar in some ways, too. Half of its 32 million population are age 15 and younger. The average life span is 52 years. Only 2% of the population are over 65. And it is 14th highest in the world for HIV/AIDS patients (USA is 9th), and is 9th in the world for HIV/AIDS deaths (USA is 21st).

Greg Gifford MD/CMO

Against these facts, the Ugandan people are struggling to improve their health care in prevention, medical and surgical curing, and relieving distress. The latter is where Palliative Care comes into service. As does the Center for Hospice and Palliative Care (CHAPC), and Rose.

Rose Kiwanuka, R.N. is a native Ugandan who lives in a small village outside the capital city of Kampala. Her nursing training includes extended study in England and additional course work that allows Rose to prescribe medications for palliative care. She works full-time as the National Coordinator of the Palliative Care Association of Uganda. She is a human dynamo. Her purview is all 80 districts in the country, 35 of which have some type of palliative care, and ten of which have well-developed programs and access to pain medications. Her small teams of volunteers, nurses, and nurse practitioners are making inroads into village health care, both directly and sometimes indirectly by being "consultants" to the local Native Healers (who are beginning to notice that western medicine can often help their patients). The Native Healers are becoming Rose's allies.

For some time the administrators at CHAPC have wanted to have a "sister hospice" in a developing country. They contacted the Foundation for Hospices in Sub-Saharan

Africa who partnered CHAPC with the Palliative Care Association of Uganda in October 2008. Rose had been hopeful for a partnership in her efforts to "bring palliative care to all of Uganda" and both she and CHAPC believe we are a perfect match. In March 2009, Roberta Spencer and Karen Smith-Taljaard of CHAPC traveled to several parts of Uganda to collect information and better determine how our agency could be of assistance.

As Roberta wrote back, "We learned much in our visit. We were especially moved by the hospitality and kindness shown to us by everyone we met. The simplicity of life and making do with what little resources they have was an additional reminder that we have much to be thankful for in our own day-to-day personal and professional lives. Finally, the overwhelming gratefulness of Rose, those she works with, and patients fortunate to receive service was an affirmation as to why The Center for Hospice and Palliative Care made the decision to establish our partnership."



Rose Kiwanuka, R.N.

Rose will be coming to South Bend at the end of October to visit CHAPC and strengthen our bonds, to meet our community resources - including you - and to explore additional support of a program with the mission: "To Promote and Support Affordable and Culturally Appropriate Palliative Care Throughout Uganda." We want her to address our medical community and will let you know where and when you can meet her and hear her speak. All of us will be the better for it.

Opportunities to assist with our Ugandan partnership are available. Please contact Mike Wargo, The Hospice Foundation, at 574.243.2059.

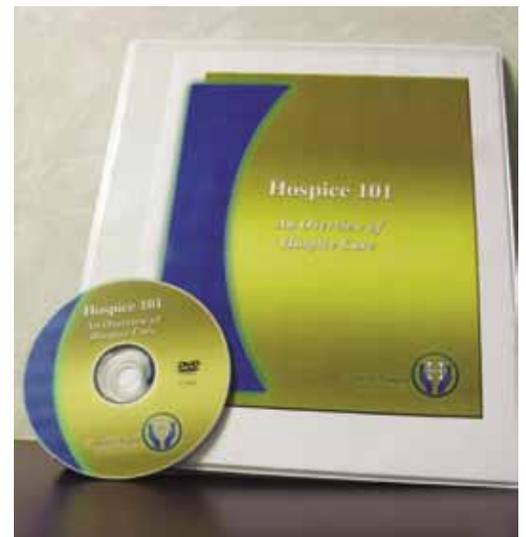
Hospice In-Service Made Easy

In response to the changes in the Conditions of Participation (COPs), the Center for Hospice and Palliative Care (CHAPC) created an In-Service DVD entitled **Hospice 101: An Overview of Hospice Care**.

"After meeting with several directors of nursing at a variety of extended care facilities, it was apparent there was a need for a more flexible way for staff to fulfill their regulatory requirements for hospice education," noted Terri Stahl, CHAPC community liaison.

"We are very excited with the final product," noted Alice Wolff, RN, ECF coordinator. "We hope it is well received by the ECFs in our service area."

Kim Lintner (lintnerk@centerforhospice.org) and Terri Stahl (stahl@centerforhospice.org), both community liaisons with CHAPC, will be making appointments with area DONs to deliver the Hospice 101 DVD. If you are interested in obtaining a DVD package for your facility, please call 574.243.3711. The Hospice 101: An Overview of Hospice Care DVD is available at no charge to area extended care facilities.



Hospice 101: An Overview of Hospice Care

Latino Patients: Improving Their End-of-Life Experience Through Clear Communication and Cultural Understanding

Communication Issues

Clinicians can improve end-of-life care for Latino patients and families by clearly communicating health information and by understanding and respecting cultural influences. This is according to recommendations published in the *Journal of the American Medical Association*.

Language barriers and/or limited health literacy can impede understanding of health status and treatment options for some Latino patients. To address language barriers, clinicians should use professional interpreters whenever possible.

Regardless of the patient's ethnicity and health literacy, clinicians are advised to:

- Use the “ask-tell-ask” model. Ask what patients understand about their condition, provide needed information, and confirm that they comprehend the information. “What have you already been told about your illness?”
- Use simple terms, not jargon.
- Limit new information to only 2 items per conversation.
- Assume that there are questions. “What questions do you have?”
- Ask the patient or family to restate information. “I’ve just said a lot of things. To make sure I did a good job and explained things clearly, can you describe to me what we’ve talked about in your own words?”

Cultural Considerations

Physicians in Latin America are less likely to disclose the truth to a patient with a poor prognosis and more likely to direct a patient's choices regarding life-extending treatments. In addition, palliative care is less available in Latin America than in the U.S. Consequently, Latino patients and families often are uncomfortable making end-of-life care decisions.

Other cultural factors can affect patient decisions:

- **Familismo:** Clinicians should be prepared to have extended families present and involved in health care decisions.
- **Machismo:** The traditional need to provide for and protect the family may lead Latino males to make the majority of the medical decisions for a female family member. Clinicians should try to speak to the female patient in private, to determine her true wishes and concerns. In addition, when a male Latino is too sick to fulfill what he sees as his family duties, he may feel shame. Clinicians should be respectful, ask about his concerns, and try to use creative ways to help him contribute to his family despite his illness.

Religious Considerations

Very religious patients sometimes insist on using all measures to extend life, stating that they expect a miracle even when clinicians have exhausted all available treatments. If the patient agrees, clinicians can bring in the patient's faith ministers, who often can help clinicians understand religious beliefs that are different from their own, while providing the patient and family with additional spiritual support.

Issue of Discrimination

Many Latinos report that they have experienced discrimination in health care situations. Because of these experiences, patients sometimes feel distrust toward

clinicians and the health care system in general and may assume that they are not being offered curative treatments because of discrimination.

To gain the trust of their Latino patients, clinicians can “state outright that they do not tolerate discrimination in their practices and that they strive to treat all patients equally,” the authors write.

Source: “Palliative Care for Latino Patients and Their Families: Whenever We Prayed, She Wept,” *Journal of the American Medical Association*; March 11, 2009; 301(10):1047-1057. Smith AK, Sudore RL, Perez-Stable EJ; Division of Geriatrics, Department of Medicine and Division of General Internal Medicine, University of California, San Francisco; Veterans Affairs Medical Center, San Francisco.

Ways Clinicians Can Help

- Be sensitive to external challenges faced by many Latino immigrants, such as geographical distance from family members, fears of deportation if the immigrants are undocumented, and perception of discrimination.
- Avoid asking questions about immigration status unless it affects treatment.
- Ask questions to help with cultural understanding:
 - “What language do you speak at home?”
 - “Were you born in the United States?”
 - “How long have you lived in the United States?”
 - “Tell me what I need to know about your culture.”
 - “What do you think is the cause of this illness?”
 - “How would this illness be treated in your culture?”
 - “How do doctors in your culture talk with people about illness?”

— Smith, Sudore, and Perez-Stable

Journal of the American Medical Association

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Staff Achievements

Gregory Gifford, MD, JD, is the new Chief Medical Officer for CHAPC. Gifford is a physician and an attorney. He is board certified in both hospice and palliative medicine and in emergency medicine. After earning an undergraduate and medical degree from Indiana University, he completed a rotating internship at St. Joseph Medical Center in Denver, CO and an emergency medical residency at Michigan State University, where he was chief resident. An interest in law led him to earn a law degree during the day while working nights at the Ingham Medical Center in Lansing, MI. After that, he became Chief of Staff and Bioethics Committee Chair at the Castle Medical Center in Ulikaiki, HI. Additionally, he served as a consultant to the Hawaii State Department of Health as the Medical Director for the state EMS System, providing advice on policy and procedures for pre-hospital transport and care. While working in emergency medicine, he became very interested in hospice and palliative care and became board certified through AAHPM in 2001. He eventually returned to his home state and was most recently employed by Columbus-based Hospice of South Central Indiana, Inc., a 29 year-old program serving 15 counties with four care offices and a 14-bed inpatient unit. Dr. Gifford's principal interests today are improving end-of-life care for patients and families along with addressing medical as well as ethical and legal issues.

Jacqueline Kronk has been named Director of Development for the Hospice Foundation. Her primary responsibilities include fundraising, donor relations and departmental management. In addition, she is responsible for the Foundation's public relations and social networking initiatives.

Donna Tieman, RN, CHPN, Terri Lawton, RN, CHPN, and Joy Barnes, RN, CHPN, recently became Certified Hospice and Palliative Nurses (CHPN). Certification in hospice and palliative care is highly valued and provides formal recognition of basic hospice and palliative nursing or administration knowledge. The purpose of certification is to promote delivery of comprehensive palliative nursing care through the certification of qualified hospice and palliative professionals.

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