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## In a Couple of Days... The benefit of early referrals

David Tribble, MD, ABHPM, FAAFP

Medical Director/Chief Medical Officer/Center for Hospice and Palliative Care

It is common for us at The Center for Hospice and Palliative Care to be invited to participate in a patient's care within hours or days of their dying. We have much to offer in that setting: relief of pain, dyspnea, restlessness, bereavement services for those remaining, and assistance with the burden of care for the caregivers, to name a few. These services are valued highly by those who receive them, and by us who provide them. These, however, are a limited subset of what is possible in terms of quality end-of-life care, limited by time, by the lack of opportunity for development of a trusting relationship, and by the lack of involvement by the entire team in the patient's progress toward death. There is only so much we can do in a couple of days...

There are a number of factors that lead to such late referrals: difficulties with prognosticating, the perception that the patient is, “not yet ready for hospice...,” concern that hospice care amounts to medical abandonment, to name a few. For the most part, these are the result of misinformation.

Palliative medicine research has shown that physicians are generally poor at predicting survival, almost always being more optimistic than actuality demonstrates. The longer and more closely a physician has known a patient, the more inaccurate the prediction, demonstrating what has been called “the conspiracy of hope.” This is not wanton Pollyannaism, it is a natural expression of a physician's wish to preserve a relationship that is valuable to him or her on a personal level. For most malignancies, there is good survival data available. Prognosticating non-cancer diseases is more difficult. In either case, palliative medicine consultation, either as inpatient or

outpatient, may be helpful in developing an accurate prognosis. Accurate prognosticating is of value, not only to the patient who must make plans and decisions, but to the credibility of the practitioner. The more solid and objective the basis for the prognosis, the less it seems arbitrary.

Not long ago, a local physician characterized his concept of hospice care to me as, “all you do is sit around and watch them die...,” hence describing hospice care as medical abandonment. We also hear, “there is nothing else I can do for you, so I am recommending hospice...” This is even supported in the current concept of the interface between curative and palliative care in which 100% of the emphasis is on cure until it is clear there is no more cure, at which point the patient is handed off to hospice (in one description, thrown over the wall). Palliative medicine asserts that patient comfort and quality of life and curative care are not mutually exclusive, that the boundary between palliation and curative care is not as sharp as this model would allege, and that, even when hope of cure is gone, all life is not lost. We do not require a DNR. A patient is welcome to redirect his care toward cure if it becomes tenable to do so, and, even when demise is inevitable, all life is not lost, and there are active goals to pursue, even if cure is not one of them. Hospice care is active enough that a recent study showed that, in several malignancies and in end-stage heart failure, survival in hospice patients was actually longer than it was for those treated by more conventional means.

It also occurs, upon occasion, that some patients admitted to hospice get better. We do not consider it a failure when a patient “graduates vertically.”

Whether or not a patient is, “ready for hospice,” is clearly tied up in the other issues. Physicians who believe the prognosis is better than it actually is, or

who misunderstand what hospice care offers may be reluctant to refer until the patient is at death's door. Patients who have an incomplete understanding of hospice benefits or who fear withdrawal of currently meaningful therapies may be resistant. Although a prognosis of six months is the Medicare norm, the patient is not obliged to be dead in six months. Medication, durable medical equipment, home nursing visits, home health aide visits, social work and spiritual care visits as well as volunteer services and 24-hour on-call availability are all available to the patient at no out-of-pocket cost, as long as they are pertinent to the identified terminal illness. If the patient changes his mind, he has the right to sign out of the program and pursue whatever additional treatments the hospice agency does not provide. Frequent in-home support improves the quality of life, decreases the need for ER visits and hospitalizations, and decreases night calls to physicians.

Care is not directed exclusively at the patient. The patient and his family (however the patient defines that relationship) are clients of the hospice, and a great deal of work goes into the preparation of the family for the patient's course, mitigating conflicts, making arrangements for the patient's dying and dealing with existential issues. This particular aspect of hospice care particularly takes time and relationship building.

At the core of all this is a patient who does not cease to be important because traditional medicine no longer offers cure or meaningful prolongation of life. The care this patient needs is available from us who specialize in its delivery. We hope that physicians who may be uncertain as to the timing of a hospice referral will feel free to contact us, particularly to contact me, [tribbled@centerforhospice.org](mailto:tribbled@centerforhospice.org), if we can be of assistance in assessing or referring a patient. We hope also, that hospice care can be presented to patients as a beneficial option rather than as the abandonment of hope. We do much better work if we mustn't try to get it all done in a couple of days...



## Looking Back at 2007

By Mark M Murray, President/CEO

Thanks to your continued support and the confidence you place in our services, 2007 was another successful year for your local not-for-profit hospice and palliative care agency. We cared for 1,484 patients and their families, the most of any calendar year, surpassing 2006 by 4%. Since our first patient was admitted in January 1980, The Center for Hospice and Palliative Care (CHAPC) has served 15,644 patients. 53% of the patients cared for over the last 27 years were admitted in just the last seven years.

### *2007 CHAPC Highlights:*

- For the first time since August 2004, CHAPC received a "no deficiencies" survey for *both* our state licensure as a home health agency and our federal certification to provide Medicare home health services. (For our state hospice license and Medicare hospice certification, CHAPC has received no deficiencies during all surveys for the last 15 years.)
- Due to its role as a leading cause of death, ESHD was targeted as our first "specialty programming" area. Valentine's Day 2007 marked the kick-off of CHAPC's "HeartWize" program. With optimal management of their care through maintenance of medication compliance, surveillance of weight, extensive patient and caregiver education, and in-home dietary management, the goal of HeartWize is to improve the quality of the patient's life and decrease or eliminate emergency room visits and hospitalizations. The HeartWize program promotes the availability of around-the-clock staffing by CHAPC, giving support to caregivers as well as relieving physicians and their staff during off hours.
- CHAPC Medical Director, David Tribble, MD, became certified in Hospice and Palliative Medicine. He joins just 2,800 fellow ABHPM physicians nationwide and became number 30 in the state of Indiana. Additionally, Tribble became board certified as a Fellow by the American Academy of Family Physicians.
- To bring a strong and single focus to our fundraising and development efforts, and plan for our long-term

future financial sustainability, CHAPC created a second and separate 501(c) 3 charitable corporation called, The Foundation for the Center for Hospice and Palliative Care, Inc.

- In June, the CHAPC Board approved a \$3 million Capital Campaign for an Elkhart Hospice House project. Construction began in late 2007 on a 12,000 sq. ft. facility with two separate wings; one for Hospice House (inpatient unit) and the other for home care staff offices, volunteer training, and bereavement services. By the end of 2007, 62% of the campaign dollar amount had been committed. This was in addition to donations of 12 acres of wooded land located off of Old US 20 (Toledo Road) near the interchange for the U.S. 20 Bypass.
- Patient family satisfaction ratings remain very high. According to the more than 300 returned Family Evaluation of Hospice Care surveys mailed during 2007, 99.99% of those responding said they had a "positive experience with CHAPC," and 99.99% said they "would recommend CHAPC to others."
- CHAPC continues to be "Indiana's Most Chosen Hospice Program." As we provide quality patient care, we continue to work toward growth by serving and meeting the needs of more patients each year. On a national comparative level, looking at annualized numbers of patients served, CHAPC ranks in the top 5% of all hospice programs in America.

These are just a few of the notable milestones from last year. We thank you once again for your continued support and encouragement. All of us at CHAPC are honored to work with you in the care of your patients. We look forward to continued success in 2008.

As always, your input and suggestions are welcomed. Please don't hesitate to be in touch. You may reach me at 800-413-9083 or [mmurray@centerforhospice.org](mailto:mmurray@centerforhospice.org).



# Inaugural 'National Healthcare Decisions Day' Set for Spring

## Nationwide publicity can provide opening for end-of-life care discussions

Leading organizations committed to increasing Americans' awareness of the importance of advance care planning have announced April 16, 2008, as the launch date for the first National Healthcare Decisions Day (NHDD).

The nationwide public awareness campaign aims to provide people with the information and tools needed to consider and complete a written medical advance directive (AD), such as a health care power of attorney and/or living will. Participants in the campaign will include groups, professionals, and volunteers at the national, state, and local levels.

"Only a small minority of Americans have executed an advance directive," says Nathan A. Kottkamp, chair of the NHDD initiative and member of the American Health Lawyers Association. "The goal for the national campaign is for millions more Americans to have conversations about their health care decisions and execute thoughtful and reliable advance directives to make their wishes known."

The anticipated national attention focused on ADs can provide physicians with the opportunity to introduce the topic with patients before a crisis, before exacerbation of or incapacitation from serious illness occurs.

For Advance Directive Packets, contact Terri Stahl, Community Liaison, 574.243.3100 or [stahl@centerforhospice.org](mailto:stahl@centerforhospice.org)

The NHDD initiative notes that according to a report published by the U.S. Agency for Healthcare Research and Quality (AHRQ) in 2003:

Less than 50% of seriously or terminally ill patients studied had an AD in their medical record.

Only 12% of those patients with an AD had received input from their physicians.

65% to 76% of physicians whose patients had an AD were not aware of its existence.

"Because physicians are in the best position to know when to bring up the subject of end-of-life care, they are the ones who need to initiate and guide advance care planning discussions," comment the authors of the report, which is entitled Advance Care Planning: Preferences for Care at the End of Life.

"As a result of National Healthcare Decisions Day," says Kottkamp, "fewer families and health care providers will have to struggle with making difficult health care decisions in the absence of guidance from the patient; and health care providers and facilities will be better equipped to address advance health care planning issues before a crisis and be better able to honor patient wishes when the time comes to do so."



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Tom Kolakovich, MD  
Associate Medical Director

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*"Increasing awareness about the importance of advance care planning is much needed and should prove to be very helpful. Patients should thoroughly discuss these plans with their loved ones (children, siblings). It is not uncommon that children, in particular, have difficulty accepting a parent's decision to forgo medical tests and or therapies. If the patient cannot communicate, it can then be difficult to work with them during these hard times."*

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## Helping You Educate Your Patients

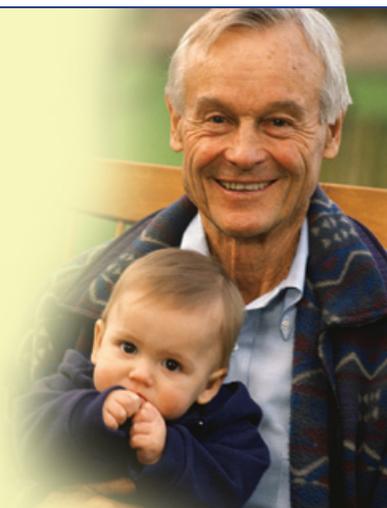
At The Center for Hospice and Palliative Care, we strive to provide you with on-going education and communication about our services. We've created a brochure we hope you will display in your waiting room or offer to patients when appropriate. We feel it's never too early to learn about hospice care and the benefits it provides to patients and families.

*Improving the Quality of Life with Comfort Care* is easy to read and understand. Your patients will find answers to commonly asked questions about hospice

care while learning more about the extensive services provided by our organization. As you know, not all hospice programs are alike. Our bereavement and spiritual care services are among the most extensive in the area.

Did you know your patients can utilize our bereavement services, at no charge, without ever having used our hospice services? Well, they can.

To request your free copies of *Improving the Quality of Life with Comfort Care* brochures, contact Terri Stahl, Community Liaison, 574.243.3100 or [stahl@centerforhospice.org](mailto:stahl@centerforhospice.org).



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We're happy to provide you with this issue of H&P. If you would prefer to receive this publication electronically, please e-mail [judda@centerforhospice.org](mailto:judda@centerforhospice.org) and in the subject line put: H&P. Future issues will be sent to your in box.

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The Center for Hospice and Palliative Care

## New Elkhart Office and Hospice House



*Progress is evident at the site of the new Elkhart office and Hospice House. To date, over \$2 million has been committed to the project.*

A \$3 million philanthropic campaign is underway to fund this facility. For more information, or to make a pledge, visit [www.centerforhospice.org](http://www.centerforhospice.org) and click on the Elkhart Hospice House banner.

**Address:** 25579 Old US 20

**Size:** 12,000 sq. ft.

**Cost:** \$3 million

**Architect:** Helman Sechrist

**Contractor:** Almac Sotebeer

### **Capital Campaign**

Campaign Chairman: Michael J. Wargo  
Honorary Co-Chairman: Arthur J. Decio  
Honorary Co-Chairman: Robert J. Deputy

### **Steering Committee**

Jeannelle Brady  
Chris Chocola  
Catherine Hiler  
Frank Martin  
Dan Morrison  
Terry Rodino  
Rita Streffling  
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