

Quality^{of} Life Matters™

End-of-life care news & clinical findings for physicians

Vol. 4, Issue 1 May/June/July 2002

Medicare Hospice Benefit 'Not Limited in Terms of Time,' Federal Agency Stresses

The federal agency responsible for Medicare has published an article in which it stresses the value of hospice care in easing the physical and emotional suffering of terminally ill patients and their families. The agency also reminds physicians and long-term care providers of the **wide availability of hospice services** under the Medicare program.

The Centers for Medicare & Medicaid Services (CMS) — formerly known as the Health Care Financing Administration — has published its article, entitled "**End-of-Life Care Enhances Dignity and Peace As Life Nears Its End,**" in periodicals such as *The Physician Executive*.

In the article, the CMS states that "**Medicare's benefit is not limited in terms of time.**"

Regarding eligibility rules, says the CMS, "the Medicare program recognizes that **terminal illnesses do not have entirely predictable courses**" and that "prognoses can be uncertain and may change."

"Thus," continues the CMS, "**there is no reason for a physician to be concerned about certifying an individual for hospice care that he or she believes to be terminally ill.**"

Upon enrollment in the Medicare hospice program, beneficiaries receive two 90-day "periods of care," followed by an **unlimited number of 60-day periods**, so long as they remain eligible for hospice recertification at the start of each period.

The governing statute of the Medicare hospice benefit states: "The certification of terminal illness of an individual

SERVICES COVERED UNDER THE MEDICARE HOSPICE BENEFIT INCLUDE:

- Physician services & nursing care
- Medical equipment and supplies
- Pharmaceutical therapy for pain relief and symptom control
- Home health aide and homemaker services
- Physical, occupational, and speech therapy
- Dietary counseling
- Social work services
- Bereavement and other counseling
- Case management

who elects hospice shall be based on the physician's or medical director's clinical judgment regarding the normal

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88% of Americans Favor Consultations with End-of-Life Care Experts

Most Want Consultation When Prognosis Is Two Years or Less

According to a new nationwide survey, nearly nine out of ten adults believe that patients with a terminal illness would benefit from a complementary consultation with end-of-life care professionals to inform patients and families of their care options and to help them make plans.

Further, 81% of these respondents think the consultation should occur when patients are given a life-limiting prognosis of two years or less. Only 14% believe it should occur when death is imminent.

In a regionally representative sample, 1,012 American adults (aged 18 years

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New 'Common Sense' Criteria Proposed for Referring Pulmonary Patients to Hospice

Chronic Obstructive Pulmonary Disease is the fourth leading cause of death in the U.S.

New, specific recommendations for identifying patients with advanced lung disease who might be appropriate for hospice referral have been offered in a paper published in the January 2002 edition of *Chest: The Cardiopulmonary and Critical Care Journal*, the official publication of the American College of Chest Physicians.

The paper includes a description of hospice services as available in the United States and reviews the use of the Medicare hospice benefit for patients with advanced lung disease, with particular emphasis on chronic obstructive pulmonary disease (COPD) — the fourth leading cause of death in this country.

The focus is not on “giving up,” write authors Janet L. Abraham, MD, of the Dana-Farber Cancer Institute and Brigham and Women’s Hospital, Harvard Medical School, Boston, and John Hansen-Flaschen, MD, of the University of Pennsylvania School of Medicine, Philadelphia.

Rather, emphasis is placed on providing — and asking patients to accept — **professional supportive care for the relief of suffering and the provision of care needs**, so that patients can accomplish their goals. “Hospice workers approach dying as an active phase of life, filled with the many goals that patients and their families wish to complete before or shortly after the end of life,” they write.

Physicians are encouraged to introduce the subject of hospice by advising their patients that **they are now eligible for additional care and support**. A physician might say:

“We both hope for the best, but we should also prepare for the worst. Your lung disease has reached the point that you could die at any time now if something unexpected comes along. If you are ready, I am willing to talk about how people with your disease die, and how best to prepare for death.”

The authors note, “**Although hospices serve dying patients regardless of diagnosis**, limited available evidence suggests that **these programs are relatively underutilized by patients dying of nonmalignant lung diseases.**”

Included among possible reasons for this underutilization of hospice for pulmonary patients are:

- Lower awareness of hospice services and eligibility criteria among pulmonologists than oncologists
- Prognostic uncertainty: the unpredictability of death from advanced lung disease
- Physician reluctance to raise the possibility of death

Unlike lung cancer patients, whose disease follows a relentless, predictable course in the last months of life, many patients with COPD or interstitial lung disease die as a result of an unanticipated acute exacerbation or intercurrent illness, such as bronchitis or myocardial infarction, the authors note. On the other hand, some patients may escape acute illness and experience unexpectedly prolonged survival.

In addition to recognizing that many patients with advanced lung disease can reasonably be expected to live less than 6 months — although some may live longer — the criteria recommended by Abraham and Hansen-Flaschen [see box] aim to match the current needs of the patient with the special expertise and resources offered by a hospice program.

For more information, go to www.chestjournal.org. Non-members may access full texts for a fee.

C R I T E R I A

Abraham and Hansen-Flaschen suggest the following criteria for identifying pulmonary patients who might benefit from hospice referral:

1. Despite an adequate trial of optimum available treatment that is acceptable to the patient, a chronic lung disease has progressed to the point that the patient may die at any time because of an ordinary intercurrent illness, such as bronchitis or pneumonia;
2. Because of distressing symptoms or a severely limited performance status, the patient can be expected to benefit from the specialized services offered by hospice programs; and
3. The patient accepts that death may be near and does not want to suffer needlessly.

“Research surveys have revealed repeatedly that most patients with COPD and other chronic illnesses anticipate their own death and welcome frank discussions and guidance from their physicians.”

— Abraham and Hansen-Flaschen

Medicare Hospice Benefit 'Not Limited in Time' (from Page 1)

course of the individual's illness," further noting that "making medical prognostication of life expectancy is not always exact."

Despite a growing appreciation for end-of-life care among physicians and health professional organizations, says the CMS, there are existing barriers to a wider acceptance of hospice care. These barriers include:

- A **reluctance** on the part of Americans **to contemplate the end of life**

- A lack of awareness that the **“covered hospice benefits are both broad and readily available virtually everywhere in the country”**

Health care professionals can also benefit from hospice services, according to the article. “Physicians and other health care practitioners, who also confront a sense of loss with terminally ill patients, can be encouraged that the Medicare program includes a hospice benefit that provides coverage for a va-

riety of services and products.”

The paper concludes with contact information for professional and national organizations that support hospice care. Such groups, says the CMS, share the same belief: **“that hospice is not about death, but rather about the quality of life as it nears its end,** for all concerned — the patient, family and friends, and the health professional community.”

The full text is available at www.hcfa.gov/medlearn/hosp_article.pdf

88% Favor End-of-Life Care Consultations (from Page 1)

or older) were interviewed by telephone in January 2002 concerning their end-of-life care preferences, knowledge of how that care is funded, and their assessment of the sources of information available to them.

REASONS CITED FOR FAVORING CARE

Those who believed patients would benefit from end-of-life care consultations cited the following reasons:

- **Increased control** over end-of-life decisions
- **Improved quality of life**
- **Alleviation of financial worry** (upon learning that the benefit is paid for by Medicare)

LACK OF AWARENESS STILL EVIDENT

Although the Medicare Hospice Benefit was established by Congress in 1982, most Americans are unaware of how hospice care is financed. A survey conducted in 1999 by the National Hospice Foundation found that 90% of Americans did not know that hospice was covered by Medicare.

According to the current study:

- Only 15% of adults know that Medicare pays for end-of-life care, and very few (3%) mention Medicaid.
- 42% think that health insurance is the primary payment source.
- 17% believe that Americans pay for such care out-of-pocket.
- 17% say they don't know or aren't sure.

“Twenty years later, people still want the same kind of care but, unfortunately, they still don't know hospice is available or how to pay for it,” says Jonathan Keyserling, who is vice president of public policy/communications for the National Hospice and Palliative Care Organization, Alexandria, VA, which conducted the survey in conjunction with Harris Interactive of Rochester, NY.

OTHER KEY FINDINGS

- **Most Americans (86%)** believe that patients with a terminal illness **would like to receive end-of-life care at home.**
- **63% consider hospice most knowledgeable** in helping terminally ill patients to stay at home with their families; 17% think physicians are most knowledgeable.
- While 62% of the population believes that health care professionals — including physicians — are **truthful with patients** about their life-limiting conditions, just 49% of those aged 55-64 years believe this to be true.
- Just under half (49%) of those surveyed think that the health care system and physicians adequately **explain the options available** for end-of-life care. But only 39% of people aged 55-64 agree.

“Americans obviously believe more education is needed for patients to understand the full range of expertise and services available from the hospice team,” concludes Keyserling.

Go to www.nhpco.org for full survey results.

RESEARCH MONITOR

Cancer Death Trajectory Is Unique Among Leading Causes of Death, National Study Confirms

The first nationwide study comparing the dying trajectory in the last year of life for cancer and the four leading noncancer causes of death has found what health care professionals have long asserted: that **among these patients, only persons dying of cancer experience a rapid functional decline in the last months of life.**

Further, this sharp functional decline was associated with both dying at home and hospice involvement in terminal care, according to Joan M. Teno, MD, MS, and colleagues at Brown University School of Medicine, Providence, Rhode Island.

“The U.S. Medicare hospice benefit was created based largely on a cancer death trajectory,” write Teno and colleagues. “However, the majority of patients did not exhibit that classic rapid functional deterioration.”

To determine national estimates of rates of functional decline, the team analyzed data on 3,614 decedents representing 914,335 deaths in 1993 from cancer

or one of the four leading noncancer causes of death:

- congestive heart failure,
- chronic obstructive pulmonary disease,
- cerebral vascular accident, and
- diabetes mellitus

Information regarding the onset and duration of difficulty with activities of daily living (ADLs) and mobility was obtained from next of kin of the decedents by the 1993 U.S. National Mortality Followback Survey [See box.]

HOSPICE CARE AND SITE OF DEATH

- While only 6.5% of those patients with no functional decline in the last five months of life had hospice involved with their care, 29% of patients with severe functional decline utilized hospice services.
- 20.3% of patients with no change in ADL impairments in the last five months of life died at home, compared with 40.7% of patients who

added three or more ADL dependencies.

Precipitous functional decline may be associated with hospice referral and at-home death because **“the rapidity of the functional decline may serve as a cue to the physician, patient, and family that the person is dying,”** comment the authors. In addition, the resulting diminished quality of life may allow dying persons and their family to become open to receiving palliative care.

Yet the majority of patients in the study did not experience a severe functional decline, note Teno and colleagues. “If this is true, perhaps the recertification process for the U.S. Medicare hospice benefit discriminates against those persons with noncancer terminal diagnoses,” they suggest.

Source: “Dying Trajectory in the Last Year of Life: Does Cancer Trajectory Fit Other Diseases?” Journal of Palliative Medicine; Winter 2001; 4(4):457-464. Teno JM, Weitzen S, Fennel ML, Mor V; Department of Community Health, Center for Gerontology and Health Care Research, Brown University School of Medicine, Providence, Rhode Island.

Cancer Trajectory Study Findings: ADL Impairments

Cancer patients were less functionally impaired than others at one year prior to death and continued to be so until the last two months of life. In contrast, noncancer patients were more impaired at one year prior to death than were cancer patients, but they experienced a more gradual functional decline.

The more precipitous decline in ADL levels experienced by cancer patients began approximately five months prior to death.

ONE YEAR PRIOR TO DEATH:

- Only 20% of terminally ill cancer patients had any ADL impairments, while more than 40% of those dying from noncancer causes were already impaired.
- The mean number of ADL impairments for cancer patients one year prior to death was just over 0.5; for noncancer

patients, it varied from 1.3 to 1.6.

- While only 13.9% of cancer patients had difficulty getting out of bed or a chair one year before death, the percentage of noncancer patients experiencing this difficulty was 35%.

THE LAST FIVE MONTHS OF LIFE:

- The mean number of ADL impairments in persons dying from cancer rose from 1.0 to 3.0; in those dying of noncancer causes, the mean number increased from 1.6 to 2.3 impairments.
- The percentage of cancer patients who had difficulty getting out of bed or a chair increased from 22.2% to 63% in the last five months of life. Approximately 50% of noncancer patients had difficulty getting out of bed in the final months of life.

RESEARCH MONITOR

Cross-Cultural Communication Techniques Can Improve End-of-Life Care

Addressing cross-cultural differences in the clinical setting can significantly improve satisfaction with the provision of end-of-life care for all parties concerned, according to a recent report in the *Journal of the American Medical Association*.

Following are some suggestions from the research team, based in Los Angeles and Charlottesville, Virginia.

RESPONSES TO INEQUITIES IN CARE

Establishing trust in the physician against a backdrop of experienced inequities in medical care is a critical challenge in cross-cultural communication. Studies have shown that African American patients, for example, are more likely to want life-prolonging treatment and less likely to have do-not-resuscitate orders than are patients of European descent. Among the stated reasons for this is a mistrust of the medical system. Physicians can:

- Address the issue directly: *"I wonder if it is hard for you to trust a physician who is not [of your background]?"*
- Explain that you will work together with the patient and family to achieve the best possible care.
- Strive to improve access to care.
- Try to understand the patient's desire for more aggressive care, and use respectful negotiation when this is contraindicated.

COMMUNICATION/LANGUAGE BARRIERS

Physicians can:

- Avoid medical jargon.
- Check for the patient's understanding: *"So I can be sure I'm explaining this well for you, please tell me your understanding about your illness and the treatment we're considering."*
- When necessary, use the services of professional translators rather than family members, especially children.

RELIGION AND SPIRITUALITY

Spiritual belief is often a source of strength to those facing the end of life. Physicians can:

- Ask: *"Where do you find your strength to make sense of this experience?"* Or: *"What is important for us to know about your faith or spiritual needs? How can we support your needs and practices?"*

TRUTH TELLING

While patient autonomy and "informed consent" are the norm in this country, this is not necessarily the case in much of the rest of the world. Many cultures believe that withholding medical information about terminal illness is more humane to the patient. Physicians can:

- Make an offer of diagnostic or prognostic information to the patient, allowing for "informed refusal." *"Some patients want to know everything about their condition, while others prefer that the doctors mainly talk to their families. How would you prefer to get this information?"*
- Use a hypothetical example: *"Others who have conditions similar to yours have found it helpful to consider several options for care to keep them feeling as well as possible, for example..."*
- Remain alert to nonverbal or indirect communications.

DECISION-MAKING STYLES

Family involvement in decision-making about end-of-life care is found in all cultures. However, many cultures view making such decisions as primarily the duty of the family, in order to protect the dying person from the burden of making difficult medical choices. Physicians can:

- Identify the key family members and include them in discussions, as desired by the patient: *"Is there anyone else I should talk to about your condition?"*
- Determine whether or not someone who accompanies the patient is to be involved in receiving information and making decisions.

USE OF HOSPICE SERVICES

The consideration of hospice care may appear to some cultures to be in conflict with the filial responsibility to care for aging parents. Physicians can:

- Emphasize that hospice is not a replacement for family care, but an adjunct or assistance: *"When the family is taking care of your father at home, hospice can help them do that."*

Source: "Negotiating Cross-Cultural Issues at the End of Life: 'You Got to Go Where He Lives,'" *Journal of the American Medical Association*; Dec. 19, 2001; 286(23):2993-3001. Kagawa-Singer M, Blackhall LJ; *Community Health Sciences, University of California, Los Angeles School of Public Health & Asian American Studies; Center for Palliative Care & Research and Center for Biomedical Ethics, University of Virginia, Charlottesville.*

PHYSICIAN RESOURCES

Expert Offers Practical Steps for Discussing Hospice with Patients

Many physicians who believe that hospice care would be appropriate for certain patients may not have had the opportunity to become comfortable conveying their knowledge in a way that patients can understand and accept. This is one cause of late hospice referrals, says Charles F. von Gunten, MD, of the Center for Palliative Studies, San Diego Hospice, San Diego.

“For most patients, referral to hospice means an increase in the intensity of services. It also means an increase in resources available to them,” writes von Gunten in an article in the March 1, 2002, issue of the *Journal of Clinical Oncology*. “If the physician is not able to convey the benefits of hospice in an appropriate situation, the patient is unlikely to accept care that will facilitate his or her optimal care.”

To assist physicians in discussing hospice referral, von Gunten has developed a six-step approach based on his own clinical experience and on protocols for the structured interview used to convey important medical information.

SUSTAINING HOPE

Essential to the success of the interview in which hospice is introduced is the physician’s understanding, not only of the potential benefits to the patient of hospice and palliative care, but also of the nature of hope, says von Gunten. “Hope is different from wishing. It is not an escape from reality; it is a way of engaging with reality in which there is an expectation that goals can be achieved.”

The objects of hope for patients with cancer, for example, can change over the course of the illness — ranging from hoping for cure or remission to hoping to set affairs in order, hoping not to suffer or be a burden, and hoping that the bereaved family will be supported. Yet hopefulness remains, says von Gunten, and the physician has an important role in sustaining and directing this hope.

The following is a summary of von Gunten’s recommended steps for discussing hospice care:

STEP 1: ESTABLISH AN APPROPRIATE SETTING

- Choose a private setting in which everyone will feel comfortable. Sit down. Ask if the patient would like anyone else to be present. If so, be willing to postpone the discussion.

“I’d like to talk to you about where we’re going with your care.”
Or, *“I’d like to review where we are and make plans for the future. Would you like your son to be here with you?”*

STEP 2: LEARN WHAT THE PATIENT UNDERSTANDS

- Ask an open-ended question to elicit what the patient understands about his or her current health status. **This is an important step and must not be skipped**, says von Gunten.

“Will you summarize for me what you understand about where we are now?” Or, *“What do you understand about your current health situation?”*

- If the patient does not share your understanding of the overall health status, determine whether or not he or she wants to hear the truth. This may be an opportunity for conflict resolution about the state of the patient’s disease, rather than the time for recommendation of hospice care.

STEP 3: DETERMINE WHAT THE PATIENT EXPECTS

- Ask patients who understand the status of their disease to consider the future.

“Have you ever thought how you would want things to be if you were much more ill? What do you see for yourself? What are you hoping for?”

- Listen. Many patients will describe their thoughts about dying. Most say they want to be comfortable, stay at home, but not become a burden.
- Clarify what is likely or unlikely to happen. Ask follow-up questions to identify discrepancies between what you expect and what the patient envisions. Many patients imagine a horrible death; describing what is likely to happen can be helpful.
- Be certain you share the same understanding of the overall goals of care. This step also allows you to gain a sense of the patient’s values and priorities.

STEP 4: DISCUSS HOSPICE CARE

- Structure the conversation by using your insights into the patient’s values and goals.

“You’ve told me that you want to be as independent and comfortable as possible. You’ve also said you’d like to spend as much time as possible with your family and avoid hospitalization. Hospice care is the best way I know of to help you achieve those goals.” Or, *“You’ve said the trips to see me in the office are more and more difficult. I believe it would be helpful to get the hospice program involved at this point.”*

“By establishing goals and introducing hospice as a way of

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PHYSICIAN RESOURCES

Discussing Hospice with Patients (from Page 6)

achieving them, it puts hospice care solidly into the spectrum of other medical therapies and programs,” writes von Gunten. “Further, having goals is a way to express hope.”

- Give information in small pieces, and in language the patient understands. Pause frequently to assess reactions, ask for questions, or elicit concerns.
- Listen carefully. Patients can have a distorted view of hospice, and some may never have heard of it. Reconfirm that hospice is a program that helps the patient and family achieve the goals just discussed.
- Clarify misunderstandings. Explain that hospice referral does not mean that you and the medical team will stop caring for the patient, or stop striving for the patient to live “as well as possible, for as long as possible.”
- Offer to ask someone from the hospice program to come by simply to explain the details.

“From what you’ve told me, I think it would be best if we got hospice involved now.” Or, “I recommend that we call the hospice people.”

STEP 5: RESPOND TO EMOTIONS

- Patients or families can experience strong emotions in reaction to a discussion of hospice. Respond sympathetically. The best initial response may be silence and the offer of a box of tissues.
- Consider commenting on the emotion.
- Acknowledge that it is difficult to discuss this issue. Reinforce this with your body language.
- Remember that most such emotional responses are short-lived. Most patients have good coping skills, and will appreciate the physician’s supportive presence while they work through the process.

A reluctance on the part of clinicians to precipitate emotions they feel unprepared to handle is one of the most common barriers to initiating a discussion of hospice, says von Gunten. Learning to respond sympathetically is the best way to overcome this barrier. “As with most aspects of being a physician, a sense of competence leads to a willingness to engage in the challenge,” he notes.

STEP 6: ESTABLISH A PLAN

- Implement a plan that is clearly stated and understood.
- If you have requested a hospice team to come by to offer information, meet with the patient afterwards for further discussion.
- Consider convening a family meeting to discuss the patient’s preferences.
- Once hospice care is chosen, share your findings with the hospice agency. Give explicit information about the communications that preceded the referral, particularly if family conflict was involved.

“Working to help patients and families achieve their goals and understand the limits of modern medical care can be rewarding,” concludes von Gunten.

For more information, access the EPEC Project’s “Module 7: Goals of Care” at www.epec.net/content/participantshandbook.html

End-of-Life Care Websites

www.eperc.mcw.edu

End of Life Physician Education Center (EPERC)

www.aahpm.org

American Academy of Hospice & Palliative Medicine

www.epec.net

The EPEC Project (Education for Physicians on End-of-Life Care)

www.nhpco.org

National Hospice & Palliative Care Organization (formerly the NHO)

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

The Hospice and Palliative Care Nurses Association

www.medicaring.org

Center to Improve Care of the Dying

www.abcd-caring.org

Americans for Better Care of the Dying

www.lastacts.org

Last Acts Coalition

www.mcw.edu/pallmed/

Palliative Medicine Program at the Medical College of Wisconsin

www.medsch.wisc.edu/painpolicy

University of Wisconsin Pain and Policy Studies Group

www.capcmssm.org

Center to Advance Palliative Care

www.stoppain.org

Pain Medicine & Palliative Care, Beth Israel Medical Center

www.growthhouse.org

Online community for end-of-life care

www.partnershipforcaring.org

America’s Voices for the Dying

End-of-Life Care Meetings for Clinicians

International Conference on Pain & Chemical Dependency. June 6-8, 2002, Sheraton New York Hotel & Towers, New York, NY. Organized by the Department of Pain Medicine & Palliative Care, Beth Israel Medical Center. Secretariat: MediTech Media Ltd.; Phone 404-233-6446; Email: info@meditech-media.com

Principles and Practice of Pain Medicine. June 20-23, 2002, Fairmont Copley Plaza Hotel, Boston, MA. Sponsor: Department of Continuing Education, Harvard Medical School. Contact: Harvard MED-CME, P.O. Box 825, Boston, MA 02117-0825. Phone: 617-384-8600; Website: <http://cme.med.harvard.edu>

10th World Congress of the International Association for the Study of Pain. August 17-22, 2002, San Diego Convention Center, San Diego, CA. Contact: IASP Secretariat, 909 NE 43rd St., Suite 306, Seattle, WA 98105-6020. Phone: 206-547-6409; Fax: 206-547-1703; Email: iaspexec@juno.com; Website: www.iasp-pain.org

14th International Congress on Care of the Terminally Ill and 2nd International Symposium on Research Methods in Palliative Care. October 5-10, 2002, Montreal, QC, Canada. Sponsor: Palliative Care Division, Department of Oncology, McGill University. Contact: Events International; Phone: 514-286-0855; Fax: 514-286-6066; Email: info@eventsintl.com; Website: www.eventsintl.com/pal02

8th Congress of the European Association for Palliative Care. April 2-5, 2003, Netherlands Congress Centre, The Hague, The Netherlands. Contact: Kenes International, 17 Rue du Cendrier, P.O. Box 1726, CH-1211 Geneva 1, Switzerland. Phone: +41 22 908-0488; Fax: +41 22 732-2850; Email: eapc03@kenes.com

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Now in its fourth year of publication, Quality of Life Matters is a periodical dedicated solely to end-of-life care news and clinical findings. It is researched and written by professional medical journalists who specialize in covering palliative care issues. Quality of Life Matters is an independent publication; it is not affiliated with any health care organization or company. The quarterly newsletter is published by Quality of Life Publishing Co., a firm dedicated to easing the way for patients with life-limiting illnesses and their families.

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