Using Clinical Scales in Your Practice

By Eugenia Smither, RN, BS, CHC, CHE, CHP, and Amy Quinn, RN, BSN, CHPN

As hospice and palliative care providers, we are still lagging behind other healthcare sectors in the use of evidence-based quality measures and standardized clinical instruments. Yet in the world of healthcare today, it’s so important that we catch up.

Delivering “patient-centered, high quality care efficiently” is at the crux of CMS’s “Vision for Healthcare in America” — with the emphasis being on efficiency. And as former CMS administrator, Dr. Donald Berwick, has noted, “efficiency is the quality dimension of our time.”

While many hospices are clearly delivering on this goal, that’s no longer enough. We must also prove that we are. And using clinical scales in our practice can help us do that.
Painting a Picture of the Patient in a Common Language

As NHPCO members are well aware, new models of care have been established under the Affordable Care Act which transfer cost and financial risk to healthcare organizations (aka Accountable Care Organizations). These organizations must now be “accountable” to one another, with the goal of achieving cost savings and improved care through better communication and clinical integration. Instead of being paid under a fee-for-service model, these healthcare organizations are being compensated based on value and achieving quality metrics.

Hospice care, of course, has always been unique — providing holistic, patient-and-family-centered care that has not been seen in other segments of the healthcare system. Because hospice providers have always been paid a flat fee for all the interdisciplinary care they provide (under the Medicare Hospice Benefit), efficiency has also become the very fabric of our operations.

Still and all, as a part of this “new” healthcare delivery system, hospice providers must be able to translate to our care partners the status of the patients we serve. And this is one of the very important ways that clinical scales can be valuable.

These instruments can help us assess, measure and monitor the symptoms and functionality of our patients and share this extensive information — in a concise and efficient manner — with all members of the interdisciplinary team as well as externally to our care partners.

These instruments also help clinical staff gain documentation and care efficiency. Once staff get accustomed to documenting patient status in the standardized way these instruments require, staff is better able to paint a comprehensive picture of the patient, and support the need (and medical necessity) for services rendered. These instruments also allow patient information to be separate from caregiver and family information — both of which are important to care delivery and our supportive documentation.

Through the use of these instruments, clinicians are also able to review the effectiveness of interventions, assist in modifications and allow for individualization of the plans of care. The clinicians are better able to anticipate future needs, educate the caregiver and family about anticipated changes, and share specific instructions about what to do as the patient declines. Additionally, clinical instruments can guide difficult conversations by allowing the emphasis to be on objectivity and assessment while still allowing the clinician to deliver care in an empathetic, compassionate way.
As National Hospice Palliative Care Month begins, first and foremost, thank you for all you do. Even though our industry is facing its share of challenges, hospices are continuing to make a meaningful difference in the lives of patients and their families.

Many hospices are also doing an exceptional job of getting local media coverage of their good work, and this publicity reflects well upon all of us. It helps raise the profile of hospice which, as we already know, is highly valued by Americans. In fact, this was recently confirmed in the research conducted by Hill + Knowlton Strategies.

As members may recall, NHPCO contracted with Hill + Knowlton to gather qualitative research that would help inform the NHPCO “Affirming Hospice” national campaign. From the firm’s research, it is clear that our messages should reinforce the unique benefits of hospice: Care on the patient’s terms — at home, free of pain, and surrounded by family.

NHPCO has already begun to integrate this messaging into communications:

- The display ads created for the 2013–14 outreach collection feature the headline, “Hospice | Care on Your Terms.”
- A banner ad, featuring this same headline, also appeared on the cover of a USA Today supplement on end-of-life care, with an estimated reach of one million readers.
- More exciting still, a 15-second video with similar messaging will run on the CBS Super Screen at Times Square throughout November and December, the height of the holiday season, reaching an estimated 950,000 people a day. (A few stills from the video are shown here.)

NHPCO also plans to expand on this messaging in 2014. And there is no better time to do this.

The new year marks a major milestone in our history — 40 years of hospice care in America! Our goal, however, is to not only promote what we’ve accomplished as an industry, but also highlight how the hospice interdisciplinary model has inspired and is reshaping healthcare. The growth in palliative care is certainly testament to this.

We will continue to update you on the Affirming Hospice campaign in the coming months. Please also consider attending MLC in late March, where we will celebrate our 40-year anniversary in multiple ways.

J. Donald Schumacher, PsyD
President/CEO
Three Excellent Scales

In 2008, CMS contracted with CCME (Carolinas Center for Medical Excellence) to develop quality measures and instruments to assess hospice and palliative care quality — come to be known as the PEACE Project (Prepare, Embrace, Attend Communicate Empower).

As part of the project, a list of recommended assessment instruments for use in end of life care were developed, and a total of 131 were compiled and reviewed. The instruments were then rated based on their feasibility (how easily can the instrument be used), applicability (does it make sense for use in end-of-life care), and reliability (will different users who use the scale get similar results), as well as their validity, responsiveness, and generalizability (can it be applied to most hospice patients).

Upon review, a group of instruments were rated higher than the rest. Of these, this article highlights three that we have found to be particularly valuable in hospice.

1 Palliative Performance Scale

The Palliative Performance Scale (PPS) is a valid and reliable way to assess a patient’s functional status. This tool is very useful in documenting a patient’s decline over the course of palliative care and can assist in prognostication.

To determine the patient’s PPS, you must evaluate his or her activity level based on several criterion.

- The first is his or her ability to ambulate. Full ambulation would be the ability to walk, unassisted and without fatigue, for extended distances. Ambulation becomes reduced when rest is required or ability to ambulate distance is limited.

- The second criterion is based on any evidence of disease. People who are unable to participate in jobs or activities which they have previously enjoyed may be less active due to their disease. (For example, is someone else taking care of the patient’s house or doing the grocery shopping?)

- The ability to perform self-care is the third criterion, such as the ability to bathe, shave, dress or do mouth-care. (For example, is the patient able to prepare his or her own meals or take medications as prescribed?)

- Intake and conscious levels are the last two criteria. The intake level should be a reflection of the patient’s intake pattern. For example, while the patient may be eating a fair amount of food, it may still be less than the amount he or she would usually consume — and not reflective of the patient’s usual appetite.

PPS is not estimated between numbers on the scale. The scale is weighted from left to right and top to bottom and can vary from day to day, but there should not be very large discrepancies in scoring from one clinician to another (i.e., ~10 percent).

Lastly, decline in PPS is a good indicator of disease progression, so you should always know the patient’s PPS when communicating with his or her physician or other healthcare staff involved in the patient’s care.

See the Palliative Performance Scale.
### Functional Assessment Staging Scale

The Functional Assessment Staging scale (FAST) was developed in 1984 by geriatric psychiatrist, Dr. Barry Reisberg. It is used to help identify Alzheimer's/dementia patients who are likely to be in the last six months of life, and therefore eligible for hospice.

The purpose of the tool is to identify the stages of dementia, much like the PPS scale is used to identify the stages of a patient’s general function. A key difference between the two scales, though, is that a patient may occasionally go up or down a little on the PPS scale, but not on the FAST scale. The FAST scale is only used for Alzheimer’s/dementia, and the trajectory of Alzheimer’s/dementia is always downward, with an occasional plateau.

The FAST scale identifies seven stages of development. When using the scale, always work from the top downward (i.e., from Stage 1 to 7):

**Stage 1:** Normal adult without cognitive decline  
**Stage 2:** Normally aging adult, with mild memory loss  
**Stage 3:** Early stage of dementia  
**Stage 4:** Mild dementia  
**Stage 5:** Moderate dementia  
**Stage 6:** Moderately severe dementia:  
   a. Difficulty dressing without help.  
   b. Unable to bathe properly or safely (e.g., inability to adjust water temperature)  
   c. Difficulty toileting properly (e.g., doesn’t wipe or flush)  
   d. Urinary incontinence  
   e. Fecal incontinence.  
**Stage 7:** Severe dementia:  
   a. Speaks fewer than six words per day or in the course of an intensive interview  
   b. Speech limited to one intelligible word per day, which might be repeated over and over  
   c. Cannot walk without personal assistance  
   d. Cannot sit upright without props  
   e. Loss of ability to smile.

See the Functional Assessment Staging Scale.
Edmonton Symptom Assessment Scale

The Edmonton Symptom Assessment Scale (ESAS) measures nine domains: pain, tiredness, drowsiness, nausea, appetite, shortness of breath, depression, anxiety, and well-being. Zero indicates there is no evidence of the symptom and 10 indicates the symptom is at maximum severity. Below is some guidance on several of these domains.

- **Pain**
  Pain is what the patient says it is. If the patient is experiencing acute pain, the clinician may see physical changes such as increased heart rate or blood pressure. However, patients experiencing chronic pain may not display any physical changes.

  While it is preferable for the patient or caregiver to communicate ratings, the clinician may use his or her assessment to assign the ratings, using objective indicators for assistance. For example, the patient can be assessed for moaning, grimacing, and guarding against painful movements. Interdisciplinary collaboration can be valuable in developing a uniform approach when clinicians must assign ratings due to the patient’s and caregiver’s inability to do so.

  Lastly, if a patient cannot place a numeric value on his or her pain, a guideline to assist the clinician is as follows:

  - Mild symptom = 1 to 3
  - Moderate symptom = 4 to 6
  - Severe symptom = 7 to 10.

- **Fatigue**
  This is a common symptom among hospice patients as they decline. Clinicians should conduct an assessment and evaluate how fatigue may interfere with the patient’s ability to perform or enjoy activities by posing questions such as these: Is the patient able to identify causes of fatigue? Is the fatigue due in any way to medications the patient may be taking? Or to treatments, poor appetite, or pain? Or is the fatigue due to the disease process or its progression? It is important to note the effects of activity on the fatigue score.

- **Nausea**
  Feelings of nausea are often tied to appetite. Appetite is the natural instinctive desire for food and should not be confused with hunger, which is the body’s craving or need for food.

  When you rate a patient’s appetite, distinguish it from the amount of food consumed or the patient’s hunger. Often people will say “I don’t have any appetite but I am eating.” Rate the patient’s appetite, not food consumption. For example, if the patient is not eating any solid food, her appetite rating would be 8 to 9, depending on her intake of liquids.

- **Shortness of Breath**
  Like pain, shortness of breath or dyspnea is a subjective sensation, and needs to be perceived and reacted to.

  For example, COPD patients often develop compensatory responses and may appear short of breath, but will not identify the symptom when asked. Shortness of breath can also be a sign of decline or a common symptom of the patient’s terminal diagnosis.

  Clinical staff should qualify the patient’s responses with observations. Also important is documenting other evidence of abnormal
breathing, if any are present. Remember too that dyspnea is subjective and can occur when oxygen saturations are excellent.

- **Depression**
  Patients often experience depression based on how the disease is impacting their day-to-day activities. Clinical staff should be attuned to vocalization of hopelessness, worthlessness, guilt, sadness, appetite changes, loss of interest, and changes in sleep as manifestations of depression. It would be important to involve a counseling member of the clinical team to further explore these symptoms.

- **Anxiety**
  Patients will often express feelings of anxiety as fear. When patients and caregivers describe a “lack of desire” to sleep or take pain medications, this too may be an expression of anxiety. Thus, it’s important that clinicians listen carefully to what is being said.
  
  Anxiety can also be a physiological response to some symptoms such as hypoxia, and can indicate a change in condition.

- **Well-being or Quality of Life**
  This domain may be the most challenging to discuss with patients. Often they are defining themselves by their disease or terminal diagnosis and, as a result, find difficulty in areas such as physical, intellectual and social health as well as emotional and spiritual health.
  
  As you might expect, ESAS can be a valuable tool in creating a symptom profile, and tracking variations in the symptoms of patients who are facing end-stage disease processes. Additionally, it can be used to evaluate the effectiveness of interventions.
  
  See Edmonton Symptom Assessment Scale (go to Appendix C on page 10).


**Others Scales Being Used in Hospice**

When we presented on this topic at NHPCO’s 2012 Clinical Team Conference, we also discussed the Modified Medical Research Council (MMRC) Dyspnea Scale and the Non-verbal AD Scale.

The MMRC Dyspnea Scale is helpful in assessing the patient’s level of breathlessness, using a scale of zero to 4 — with zero indicating the patient only gets breathless with strenuous activities, and four indicating the patient is too breathless to leave the house or perform basic self-care such as dressing.

The Non-verbal AD Scale helps clinicians track a patient’s breathing as well as negative vocalization, facial expressions, body language and consolability:

<table>
<thead>
<tr>
<th>Non-verbal AD Scale</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative Vocalization</td>
<td>None</td>
<td>Occasional moan or groan. Low level of speech with negative or disapproving quality.</td>
<td>Repeated troubled calling out. Loud moaning or groaning. Crying.</td>
<td></td>
</tr>
<tr>
<td>Facial Expression</td>
<td>Smiling or inexpressive.</td>
<td>Sad, frightened, frown.</td>
<td>Facial grimacing.</td>
<td></td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to console.</td>
<td>Can be distracted or reassured by voice or touch.</td>
<td>Unable to console, distract or reassure.</td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

During our presentation, we also asked the members in our audience what other instruments were being used in their programs — and they shared the following:

- Faces, Legs, Activity, Cry, Consolability (a pain scale for non-verbal patients)
- Wong-Baker FACES Pain Rating Scale (for pediatric patients)
- Karnofsky Performance Status Scale (for prognostication)
- New York Heart Association Functional Classification System
- Modified Borg Dyspnea Scale
- Clinical Frailty Scale (for functionality)
- Missoula-Vitas Quality of Life Index.
Tools for Improvement — But Not an End Point

As hospice and palliative care providers, we are just beginning to integrate the use of standardized rating scales for symptoms other than pain. As such, it is very important to understand the limitations of current clinical instruments and to realize that there may not be instruments available that fit all of your clinical needs. Think of clinical scales as a tool for improvement. Remember too that measurement is simply a tool. It is not the end point — practice improvement is.

If you approach measurement with a spirit of curiosity (rather than judgment), and you make it practical (rather than cumbersome), it will enlighten and energize your efforts to create high-quality care.

So utilize standardized rating scales as a part of your assessments! They are designed in such a way that the questions, the conditions for administering them, the scoring procedures, and the interpretations are consistent, thus ensuring that they are administered and scored in the same way every time for every patient.

By utilizing this systematic approach in your practice, you will begin to see a pattern of consistency emerge that tells the story of your patients, their responses to interventions, and the outcomes of the care that you are providing.

For Future Reference

The authors presented on this topic at the NHPCO 2012 Clinical Team Conference and the session is now available on CD or as an MP3 file. To purchase it (Members/$10), visit www.dcp providersonline.com/nhpc o, select 2012 CTC, and enter “9C” in the Keyword Search. Then scroll to the session listing, “Using Clinical Scales in EOL Care.”

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WHV Partners:

Taking Their Mission Seriously

Due to the efforts of Suncoast Hospice, 91-year old “Mac” finally received nine military service medals that were never sent to him. And because of Hope HealthCare Services, numerous Veterans who are now at the end of life are being thanked for their service in the most honorable of ways.

Like 2,000 other hospices around the country, Suncoast Hospice and Hope HealthCare Services participate in NHPCO’s We Honor Veterans (WHV) program — an initiative that is bringing needed awareness to the special needs of Veterans and encouraging hospices to meet those needs in a variety of ways.

In recognition of Veterans Day on November 11, please take a closer look at these stories about “Mac” and “Hope’s Honor Guard” — both are moving examples of how hospices are helping Veterans feel valued and find closure as they near the end of life.
“Mac”

McPherson Plecker — known fondly as Mac — served as a machinist mate on the World War II Navy destroyer, USS Schley, and spent nearly four years as a prisoner of war in Japan and China.

After the war, he submitted his paperwork to receive his service medals. But he, like many other Veterans, never said a thing when they failed to arrive.

Fortunately, he finally did — during conversations with members of his care team at Suncoast Hospice. Upon hearing of the missing medals, the team took the lead in correcting that oversight, with help from Veteran liaison, Daphni Austin, the offices of former Congressman Michael Bilirakis, and numerous others.

On September 14 —about 70 years after submitting his paperwork — Mac was treated to a full military ceremony at a special outdoor venue in Largo, Florida. USAF Veteran General James B. Davis read the POW Prayer, and Congressman Bilirakis, now retired, presented Mac with all nine medals.

“They didn’t forget us and they really do care,” Mac shared with attendees.

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Hope HealthCare Services formed an Honor Guard (HG) in 2009 to conduct a brief but poignant ceremony to honor the Veteran patients under its care.

The HG is made up of volunteers who are Veterans themselves or who have expressed interest in supporting Veteran patients. Additionally, there is a pool of volunteers who make patriotic quilts in the colors of the flag and “camo-material” buddy bears that are given to the patients during the ceremony.

“We developed the HG ceremony over time, replicating the model of ceremonies we experience in the military,” says outreach chaplain, Jonathan Scalone, MA., DMin., who is a retired lieutenant colonel in the United States Air Force. “But we also usually find out personal aspects of the Veteran patient’s experience and weave that into the presentation.”

The ceremony, which typically lasts about 20 minutes, is coordinated with the patient’s family so it can be scheduled at a time convenient for them. Once the time, date and place are set, a blast email is sent to HG volunteers, asking whomever is able to attend. “Usually within an hour we will reach our goal of having at least three HG volunteers present, with one representing the Veteran patient’s branch of service,” says Scalone.

“One of my most favorite experiences with HG involved a Veteran patient who had become non-responsive to touch and verbal stimulation,” Scalone recalls.

“We asked his daughter, who was his only living relative, if she would like the HG ceremony for her father and she agreed. When we arrived to perform the ceremony, the patient was comfortable, lying in bed with both hands by his...
sides and beneath the bed sheet. The ceremony was conducted as usual, but in this case, the HG leader spoke softly into the patient’s ear. Toward the end of the ceremony, when the HG saluted the patient, the patient brought his right hand slowly out from under the sheet and returned the salute. All of us were stunned to tears.”

**Learn More About WHV and Enroll Too**

To learn more about the ways hospices can support Veterans — from using the WHV Military Checklist at intake to awareness of common psychosocial issues — visit www.wehonorveterans.org.

For information about participating in the program, visit wehonorveterans.org/enroll.

**WHV Social Media Campaign**

On Veterans Day, as well as in the days leading up to this national holiday, NHPCO’s We Honor Veterans team will be posting three poignant messages on Facebook and Twitter:

Download the messages, available as JPEGs, from the Outreach page of the NHPCO website, and use them in your social media too.

Or follow We Honor Veterans on Facebook (facebook.com/wehonorveterans) and Twitter (@wehonorveterans).
Helping Children Grieve

By Robin Fiorelli, LCSW, with Rex Allen, MA; Patti Anewalt, PhD, LPC, FT; Diane Snyder Cowan, MA MT-BC; Brenda Kenyon, MSW, LCSW; and Terri Ray, MA, NCC, LPC, ACS.

The hospice IDG can often be challenged when it comes to meeting the needs of grieving children. Bereaved children may experience the pain of loss earlier than we might otherwise expect. They may not completely comprehend the meaning of ‘gone for good.’ And for many, the loss can prematurely shatter their innocent belief that their parents will be there to care for them forever.

The adults who listen and take their cue for action from the children themselves, soon learn that what grieving children need most is unconditional love, reassurance that they will be cared for, and inclusion in the mourning process.

For example, when adults speak honestly to children about death, the child begins to understand death as a natural part of life, instead of something to be feared or something that happens to other people. This gives children the time to prepare for the impending death and properly mourn.

This article outlines the typical emotional, physical and behavioral manifestations of children’s grief and offers guidelines for effective intervention.

Recognizing a Child’s Typical Cues

Some of a child’s grief reactions occur immediately while others may occur at a later point. In general, children’s grief tends to manifest in physical and behavioral expression rather than verbal expression.

In addition to developmental level and chronological age, the main factors that influence how children grieve include their relationship with the person who has died and the nature of the death; their own personality and previous experiences with death; their religious and cultural beliefs; and input from the media. But, above all, it is what they are taught about death and grief from adults in their community of support that will impact them the most.

*The National Council of Hospice and Palliative Professionals (NCHPP) is comprised of 15 discipline-specific sections that represent the staff and volunteers who work for NHPCO provider-members. To learn more about this NCHPP Section, visit the NHPCO website.
Below are some guidelines, based on the child’s chronological age:

**Infancy to Age 2**

Babies do not have the cognitive capability to understand an abstract concept like death. And because they function in the present, babies will become acutely aware of loss and separation when someone significant dies.

When they experience the loss through any disruptions to their nurturing routine — including the emotions and behaviors of significant adults around them — their reactions include irritability and protest, constant crying, a change in sleeping and eating habits, decreased activity, and weight loss.

**Preschool (Ages 2-4)**

“When will my mommy be home? How does Grandma eat or breathe in heaven?”

Preschool children do not comprehend the concept of “forever.” For this age group, death is seen as temporary and reversible.

Because preschoolers tend to be present-oriented, their grief reactions are brief but can be very intense. They are learning to trust and form basic attachments and, thus, when a significant adult dies they become very concerned about separation and altered patterns of care.

They also respond to the emotional reactions of adults in their life, and may cry or throw a tantrum because they are concerned or want to distract the adult from difficult emotions.

Typical grief responses include confusion, frightening dreams, or regressive behaviors such as clinging, bedwetting, thumb-sucking, inconsolable crying, temper tantrums and even withdrawal from others.

**Early Childhood (Ages 4-7)**

“It’s my fault. I was mad at my mother once and I told her I wish she would die. Then she did die.”

Children in this age group may feel responsible for the death, believing that negative thoughts or feelings they had about their loved one caused his or her demise.

This “magical thinking” stems from the belief that everything revolves around them and they can control what happens. Even when children are exposed to death through the media or at school, they still may believe that if a person is careful enough, he or she can avoid death.

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They may also connect occurrences that do not have anything to do with each other. If a child bought a toy the day her sister died, for example, she may attribute the toy to causing the sister’s death, especially if the real cause of the death is not fully explained to her.

Sometimes children at this age can appear unaffected by the death and act as if nothing has happened. However, this doesn’t mean that they are unaware of it or have accepted the death. It may just signify their inability in that moment to acknowledge the painful reality. They also may model their grief reaction after the other adults in their lives, feeling uncertain about how to express grief feelings themselves. Children at this age also tend to be fearful that other loved ones will leave them and will sometimes form attachments to people who resemble the deceased in some way.

**Middle Years (Ages 7-10)**

“Do fingernails and hair keep growing when you die?”

This age group may want to see death as reversible, but they also begin to see it as both final and universal.

They sometimes visualize death in the form of a tangible being, such as a ghost or boogeyman. They may also be curious about the details of the death, and may ask candid questions.

Even though they know death can happen, they often don’t believe it can happen to them or someone they love. They also might view death as a punishment, particularly before age nine. Middle-aged children often become concerned with how others are responding to the death and may fear that they or other loved ones will die.

Death may be play-acted in children at these ages, especially for those who have difficulty expressing feelings verbally. As a means of idealizing and maintaining a bond with the deceased, middle-aged children may also try to assume the family role and/or tasks of the deceased as well as their mannerisms.

Some children in this age group may act out their anger and sadness and experience difficulties in school due to a lack of concentration. On the other hand, they may appear indifferent, or withdraw and hide their feelings. Other typical
responses include shock, denial, depression, changes in eating and sleeping patterns or regression to an earlier developmental stage.

**Pre-Adolescent (10-12)**

“None of my friends could ever relate to what it’s like losing their dad.”

Pre-adolescents are establishing their own identity. They are increasing their independence from the adults in their lives while increasing their dependence on peer groups.

At this age, they commonly cover up feelings about their loss so as not to appear “different” or “weak” in front of their peers. They may express their grief in such uncharacteristic ways as angry outbursts, irritability and bullying behavior.

Feelings may also be exhibited through physical complaints, moodiness, changes in sleeping and eating patterns, indifference toward schoolwork, or isolation from their peers. They may have concerns about how the household will survive without the deceased or they may have questions about religious and cultural beliefs related to death.

**Normal – But Not If Prolonged**

The developmental responses outlined here are typical and normal responses to grief in children. However, it is important to note that if any of these responses are prolonged or pervasive — affecting the child’s ability to function normally in school or with peers — it may be an indication of complicated grief and assistance should be sought.

**A Case Considered**

Grace is a 33-year-old mother of two — a 6-year-old son and 9-year-old daughter. She and her children have been living with her mother for the last four years while Grace has battled breast cancer.

When doctors told Grace that she was dying and only had a few months to live, both she and her mother struggled to accept the prognosis. While the children knew their mother had cancer, Grace and her mother refused to tell them about the prognosis.

They also refused counseling for themselves, but wanted counseling for the children who were displaying feelings of anger and sadness that were interfering with their schoolwork.

On the counselor’s early visits, Grace’s mother would open the door and whisper, “It’s been a real bad day.” Then she would disappear. Grace was often resting and didn’t want to be involved with the visit. The counselor...
learned quickly that both children suspected their mother was dying, and they believed she might die soon. Both worried who would look after them when she died. The boy wanted to live with his father, but the daughter wanted to stay with her grandmother. They both worried about whether they would get to say “goodbye” in a way that was satisfying to them. They felt disloyal in asking about the situation and angry about not being told.

The counselor suggested the children write a letter to their mother as a way to start communicating with her. After reading the letters and realizing that her children already knew that she was dying, Grace was able to let her guard down. They all were then able to slowly begin the process of saying goodbye. The counselor gave the children tracing paper and a pencil to trace their mother’s hand as a way to create a memento. This was a significant step for all involved.

As this case study illustrates, whenever possible, it is important to prepare children for the death of a loved one before the death occurs.

First, asking a child what he or she knows about a loved one’s illness allows the adult to discover any misperceptions the child may have, and can help determine where the discussion should start.

The information shared with the child should be presented in a gentle, calm manner, allowing the child to voice questions and concerns. Children can usually absorb only a little information at a time, so it is helpful to look for “teachable moments” when the child seems open to learning.

Explain that all living things must die. Nature can be utilized as a means of introducing the cycle of life and death to the child, using plants and insects as examples. Tell the child that because people are living things, they die too. Remember to explain that the images of death that the child may see on TV cartoons are not authentic and that death is irreversible. It can be explained that while people usually live a long life, someone who develops a very serious illness can die before becoming old. Using several adjectives like “very, very sick” or “very, very old” helps the child distinguish between someone with a common cold versus someone with a terminal illness. The child should be reassured
that this is not a punishment, or God’s (or anyone else’s) fault, but sometimes just happens.

If a child is old enough to understand what is happening when a loved one is dying, and both the child and the dying person would like to see each other, the child should be allowed to visit. Just be sure the child is prepared for what he or she might see and/or hear and what feelings might be experienced. And, depending on the age of the child, it may be advisable to keep the visit short.

Visiting with a dying loved one may be a way for a child to understand the reality of the death, and a way for important communication to take place. The key is that the visit must be the child’s choice. If the child does not want to visit, a supportive adult should attempt to elicit why the child is resistant, but the child’s wishes should be honored.

Throughout the illness, a child should be told about changes in a loved one’s condition as they arise. A child should also be allowed to care for a loved one in a way that he or she chooses, be it through writing cards or bringing the loved one a glass of water or tissues. Sometimes, caring for a dying loved one allows a child to feel less helpless.

### Some Effective Interventions

Once a loved one has died, it’s critically important to let children express their grief in their own way, in their own time. Never pressure a child to resume their normal activities if they are not ready. Children tend to have “grief bursts” followed by play and normal activities. While they may not be able to succinctly verbalize what they are feeling, they may demonstrate their feelings through their behavior and play.

Children need to feel that it’s okay to talk about death and grief. However, if a child does not want to share their feelings, their wish should be respected. Adults should let the grieving child know they are available to help and that any feelings they have, such as anger, sadness, fear or regret, are normal. Hugging and touching helps grieving children feel secure in expressing their emotions and also reassures them that they are indeed loved and will be cared for. Children are most often comforted by familiar surroundings and routines, and separation from other loved ones during the grief period may increase their fears about abandonment.

Messages relayed to a grieving child — such as “You’re the man in the family now” or “Be a good

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**What Families Can Do**

- Suggest children put their feelings and thoughts down on paper, through words or pictures, or write a letter to their loved one.
- Assure children that it’s okay to have fun. It’s even okay not to think about their deceased love one for a while.
- Encourage physical activity, such as walking or biking.
- Cook favorite foods and/or re-visit places that were enjoyed as a family.
- Decorate a memory box together and fill it with mementos of the loved one.
- Create a memory bracelet as a reminder that bonds continue.
- Make a memorial garden, marking the loved one’s initials and date of birth on adorning stones.
- Don’t hesitate to visit the gravesite.

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*continued on next page*
girl. Your Mommy needs your help now more than ever” — suppress grief expression and set up unfair expectations of children. Adults should gently intervene if they observe a child taking on the roles and tasks of a bereaved adult, particularly the role of the “confidante” or partner if the other parent has died.

It’s also important that adults not hide their own feelings of grief. If they do, they teach the grieving child that experiencing these feelings are not okay — that they’re something to be ashamed of or to be kept to oneself. It is also true that grieving adults should not grieve profusely and at length in front of a child since it might frighten and worry the child.

Religion is an important source of strength for many adults and children during the grief process. And like adults, children should be allowed to express their religious and spiritual concerns. Children, however, take things literally, so explanations such as “It is God’s will” might be frightening or confusing, particularly if religion has not played an important role in the child’s life. Be sure to ask the child how he or she perceives your explanations about the death.

**Special Considerations**

Children should be given the choice as to whether they wish to attend a funeral or memorial service. If they wish to, they should also be asked how they want to be involved.

If it is the child’s first experience with a funeral, adults should explain what will occur and what they and others may be feeling. Perhaps the child could write a note to include in the casket or participate in the service. Particularly with young children, it is helpful if someone who is less directly affected can be available to attend to the child’s needs, so the family has time with their own emotions.

Although children will miss their loved one and will know that holidays will be different, they may still want to celebrate them. Holiday rituals that included their loved ones could be altered and new rituals developed. Mother’s and Father’s Day can be particularly difficult for children who have experienced the death of a parent. Children may want to visit the cemetery or a special place where they have positive memories of their parent. If there is a special event that honors parents, they may wish to
A Great Tool for the Clinician

A Play Kit can be a helpful tool in the clinician’s work with grieving children, and might contain all or some of the following items:

• Stuffed animals and pillows
• Books on various types of illness and loss
• Grief coloring books, journals and activity books
• Blank paper, stationery, pipe cleaners, markers, crayons, colored pencils, pencil sharpeners
• Fabric markers and pillowcases
• Mourning bracelets
• Puppets, dolls, play figurines
• Grief games, such as The Goodbye Game, Winning at Loss, Memory Garden, Bereavement Healing, and Doggone Grief
• Plastic tub of sand with figures for sand-tray work
• Stickers of words, animals, or pictures
• Pre-formed masks that can be individualized with paint or markers
• Items found in nature, such as rocks, shells, branches, leaves.

Where to Find Them:
NHPCO Marketplace carries several excellent books, including Healing Children’s Grief (Members: $27.65); Helping Teens Work Through Grief (Members: $ 23.95); and Jeremy Goes to Camp Good Grief (Members: $14.15). For additional resources, visit www.nhpco.org/marketplace.

Additional resources can be found at Centering Corp., Compassion Books, Griefwatch and the Sesame Street website.

They may wish to identify a ‘substitute’ mother or father

identify a “substitute” mother or father who can accompany them and support them through the event.

Children often need extra reassurance and support during the first anniversary of the death. They may want more hugs and support in order to affirm and strengthen their relationship and connection. For example, children often want to celebrate the birthday of their loved one by baking a cake, making a gift and sharing memories.

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When a Child has Healed

Author and renown professor of psychology, J. William Worden, has shed important light on the process by which children come to accept a significant loss and the understanding that the death is final.

According to Worden, most children describe a “new normal” as they begin to adapt. They still think about their loved one and understand that their life has been changed, but they begin to reconstruct a life without their loved one in it. They begin to feel secure about their future — that they will be taken care of and will have their needs met by other significant adults who are available for support.

Older children sometimes state that, in going through their grief experience, they have become more compassionate toward others and more tolerant of other problems and challenges in their own lives.

Robin Fiorelli, Patti Anewalt, Diane Snyder Cowan, Brenda Kenyon and Terri Ray serve on the Bereavement Professional Steering Committee of NHPCO’s National Council of Hospice and Palliative Professionals. Rex Allen serves as the Section chair as well as the Council vice chair.
Booklets to help hospice patients and families feel more prepared and confident as caregivers (while easing staff workload)

Used by over 600 hospices to support clients and increase referrals.

Free samples: www.limbertwig.us/nhpco

Limbertwig Press
Small books, big heart.

866-563-2143 or leigh@limbertwig.us
NHPCO honored excellence in research and volunteerism at the Clinical Team Conference in late September. For the benefit of those members unable to attend, join us in recognizing the four award recipients.

Volunteers are the Foundation of Hospice Award

**Patient/Family Service:**

**Cecil Bartlett**

Casa de la Luz Hospice, Oro Valley, AZ

Cecil Bartlett has contributed more than 500 hours each year since joining Casa de la Luz in 2008. He is active in respite and vigil care, gives time every week at the inpatient unit, serves at the hospice’s memorial services, and much more. As a Navy Veteran, he also supports the hospice’s work as a We Honor Veterans partner, and was the first Casa de la Luz volunteer to digitally record a dying Veteran’s memories.

“I’ve begun to realize how wonderful it is to be part of someone’s life at the time they need a friend most,” he said.

**Organizational Support:**

**Opal Phillips**

Hospice of the Bluegrass, Lexington, KY

Since 2002, Opal has provided over 5,000 hours of volunteer service in a variety of important ways — from providing companionship to hospice nursing-home patients to offering transportation services, and conducting oral history projects. She has also taken the lead at community education events focused on advance care planning and has supported the hospice’s work as a We Honor Veterans partner.

“Being a hospice volunteer allows you to become ‘soul friends,’ not just surface friends,” Opal said.

**Teen Service:**

**Christina A. Solazzo**

Suncoast Hospice, Clearwater, FL

Christina has worked in nearly every capacity of Suncoast’s teen volunteer program. She took a lead role in the “Cheer Team” that serves patients in nursing homes and inpatient centers and has used her musical skills to benefit the Music at the Bedside Program. Most notably, she helped a patient realize a long-held wish to tell her life story and have it published — an 18-month project that, through the Wish of a Lifetime Organization, made it into print.

She is now a freshman at College of Wooster. While unable to accept her award in person, she shared a video message with attendees.
Distinguished Researcher Award

Honoring substantial contributions to hospice palliative care through research.

Vincent Mor, PhD
Professor of Medical Science, Health Services, and Policy and Practice, Brown University

For the past 30 years, Dr. Mor has focused his research on the impact of healthcare services on frail and chronically ill patients, and his contributions have improved the care that many people have received. Among his notable contributions was work as a principal investigator in the National Hospice Study (1980–83) which provided an initial evaluation of hospice care under the then-new Medicare Hospice Benefit. He has also been principal investigator of nearly 30 NIH-funded grants, and continues to influence the decisions of policy makers on hospice care. Learn more about Dr. Mor’s work on the Brown University website.
NHPCO Webinars bring you and your staff expert guidance from nationally recognized authorities on important topics of the day — at rates as low as $78 per Webinar. They also offer CE/CME credit, depending on the topic.

Two Webinars are offered each month — with one focusing on an interdisciplinary topic and the other on a quality or regulatory topic.

Keep in mind that the topics are generated and vetted by your peers. The annual calendar is developed with input from several NHPCO Committees as well as from the Educational Needs Assessment Survey.

**Dates and Time**

The Interdisciplinary Webinar usually falls on the second Thursday of the month, while the Quality and Regulatory Webinar falls on the fourth Tuesday. The dates may vary, however, depending on holidays and conflicts with NHPCO national conferences and other events — so be sure to check the 2014 schedule posted online).

All Webinars are held from 2:00 to 3:30 p.m., ET — with the option of purchasing MP3 recordings for future reference.

**Member Rates**

24-Webinar Package:
- $1,870 ($2,130 with MP3s for your library)
- Book by 12/31/13 and pay $1,700 ($1,940 with MP3s)

12-Webinar Package:
- $990 ($1,120 with MP3s for your library)
- Book by 12/31/13 and pay $900 ($1,020 with MP3s)

6-Webinar Package:
- $495 ($560 with MP3s for your library)
- Book by 12/31/13 and pay $450 ($510 with MP3s)

Single Webinar:
- $95 ($105 with MP3s for your library)
- Book by 12/31/13 and pay $85 ($95 with MP3s)
Affordable Training for Multiple Staff

The Webinar rates shown are for access from a single computer. But from that computer, you can invite as many staff, volunteers and community partners as you want to view the Webinar — so it’s an affordable way to train large groups.

If you’d also like specific staff to access the Webinar(s) from multiple computers (whether the staff is in the same building or at different locations), you can purchase additional access.

For Webinar details or to register, visit www.nhpco.org/webinar.

continued on next page

2014 WEBINAR TOPICS

<table>
<thead>
<tr>
<th>Interdisciplinary*</th>
<th>Quality and Regulatory*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>January</strong></td>
<td></td>
</tr>
<tr>
<td>Persuading Physicians to Engage Palliative and Hospice Care Earlier: The Anti-Death Panel Approach</td>
<td>MAC, ZPIC, UPIC, MIC, RAC, CERT and Other Auditors: What Does It All Mean?</td>
</tr>
<tr>
<td><strong>February</strong></td>
<td></td>
</tr>
<tr>
<td>Don’t Forget the Family and Caregivers: Best Practices in Interdisciplinary Care</td>
<td>Hot Topics in Regulatory and/or Quality Matters</td>
</tr>
<tr>
<td><strong>March</strong></td>
<td></td>
</tr>
<tr>
<td>Unique Bereavement Needs of the Elderly: Understanding Them and Responding Appropriately</td>
<td>In the Driver’s Seat: Let Your Data Drive Your Improvement Efforts</td>
</tr>
<tr>
<td><strong>April</strong></td>
<td></td>
</tr>
<tr>
<td><strong>May</strong></td>
<td></td>
</tr>
<tr>
<td>Depression in Patients and Families: Assessment, Intervention, Responsibility</td>
<td>Hospice Diagnosis Coding and Determining Relatedness</td>
</tr>
<tr>
<td><strong>June</strong></td>
<td></td>
</tr>
<tr>
<td>Artificial Nutrition and Hydration: Current Practice and Future Thinking</td>
<td>Whistleblowers, False Claims Act and Other Legal Issues — What’s a Hospice to Do?</td>
</tr>
<tr>
<td><strong>July</strong></td>
<td></td>
</tr>
<tr>
<td>“To Smell the Roses:” Complementary Therapies in Interdisciplinary Care</td>
<td>Your QAPI Program: Is It All That It Could Be?</td>
</tr>
<tr>
<td><strong>August</strong></td>
<td></td>
</tr>
<tr>
<td>After Death: Essential Information for Hospice About the Funeral Service Industry</td>
<td>Hot Topics in Regulatory and/or Quality Matters</td>
</tr>
<tr>
<td><strong>September</strong></td>
<td></td>
</tr>
<tr>
<td>Challenges in End-Stage Heart and Lung Diseases: Providing the Best Care Possible</td>
<td>New Guidelines for Cost Reporting: Do You Know Them?</td>
</tr>
<tr>
<td><strong>October</strong></td>
<td></td>
</tr>
<tr>
<td>“What’s Wrong with My Mommy?” Caring for the “Little” Family Members</td>
<td>Medicare Part D and Other Pharmacy Issues: Operating Within the Regulations</td>
</tr>
<tr>
<td><strong>November</strong></td>
<td></td>
</tr>
<tr>
<td>Mental Illness at the End of Life: Improving the Practice of Interdisciplinary Team Members</td>
<td>Quality Reporting Strategies: Current and Future</td>
</tr>
<tr>
<td><strong>December</strong></td>
<td></td>
</tr>
<tr>
<td>Interdisciplinary Team: Function, Practice and Excellence — How Do You Measure Up?</td>
<td>Is It Really a Terminal Illness? Certifying and Recertifying with Confidence and in Compliance</td>
</tr>
</tbody>
</table>

*Webinars offer continuing education credit for professional disciplines, depending on the topic and objectives. Please see the NHPCO website for the 2014 schedule and to learn about the CE/CME credit being offered and the associated fees.
NHPCO’s two primary conferences — MLC each spring and CTC each fall — not only offer important educational content and networking opportunities, but also help managers, leaders, interdisciplinary team members and administrative staff in less tangible ways — from thinking more broadly and beyond their usual purviews to helping them get back in touch with the “heart of hospice.”

**Coming in March:**

**Management and Leadership Conference**

**Preconference Dates:**
March 25–26, 2014

**Main Conference:**
March 27–29, 2014

Gaylord National Resort and Convention Center

_National Harbor, Maryland_

This conference will celebrate 40 years of hospice care in America — and feature a new format for the National Hospice Foundation Gala that will be open to all conference attendees. Dr. Nancy L. Snyderman, chief medical editor for NBC News, will deliver the opening plenary.

**Coming in October:**

**Clinical Team Conference and Pediatric Intensive**

**Preconference Dates:**
October 25–26, 2014

**Main Conference:**
October 27–29, 2014

Gaylord Opryland Resort and Convention Center

_Nashville, Tennessee_

While the Gaylord is known for its exceptional facilities, the Nashville resort is reputed as the “best of the best.” To set the stage for this event will be country music icon, Naomi Judd, who will deliver the opening plenary.

As more information about upcoming conferences becomes available, it will be posted at [www.nhpco.org/conferences](http://www.nhpco.org/conferences).
Photos and Feedback from September 2013 CTC

The Photos

NHPCO has compiled a collection of photos from the Clinical Team Conference (CTC) that was held in Kansas City in late September. These photos capture the energy and camaraderie that NHPCO conferences are known for.

Take a peek now!

The Feedback

At a concluding networking session, NHPCO asked attendees to name three things they learned and plan to share with their colleagues back home. Here’s some of their feedback:

“Use NHPCO Webinars for community teaching and PR”

“Help chaplains have stronger documentation”

“Share, share, share. Don’t keep all the information to myself”

“Make use of the NHPCO Disabilities Outreach Guide”

“Educate staff on the normal reactions to loss”

“Alert my staff on how to access the NHPCO website”

“Try out the new NewsLine App for iPads and iPhones”

“Encourage our leadership team to review the NHPCO website every week.”

“Document eligibility for hospice more effectively”

“I want to get involved in NCHPP!”

“Ask my CEO about joining the WHV Program”

“Educate staff in a positive way on ‘our new normal’”

“It helps so much to see that everyone else I connected with is facing the same challenges”

“Why isn’t the rest of my team here?”
DOWNLOAD
Our Free NewsLine App

Members with iPads and iPhones can now access NewsLine right from their devices — with NHPCO’s free NewsLine App:

**Features**

- Access all issues since January 2013.
- Read the issues online, or download them to your personal library for access offline.
- Share the articles via email, Twitter and Facebook.
- Print text-only copies of feature articles from Safari (by selecting the ‘Print This Article’ button at the end of each article).
- Keep tabs on other NHPCO news by selecting “News” from the App’s menu bar. It lists all posts to the NHPCO blog.

**Compatibility**

- This NewsLine App requires iOS 5.0 or later, and is compatible with iPhone, iPad, and iPod touch. An Android version will be released at a future date.

**Questions or Comments**

- Email the NewsLine team at newsline@nhpco.org.

*Download the App Now!*
NHPCO is proud to showcase the winning photographs and social media videos from the 2013 Creative Arts Contest. Each entry is a true testament to the talent and creativity of our many members across the country.
Photography – Adult Category

FIRST PLACE:

*All Visitors Welcome*

Judy Lang
Hospice of Northwest Ohio
Perrysburg, OH

“They say a picture is worth a thousand words… In April a special guest stopped by to visit his long-time friend. Despite the cold temperatures, Smokey from Little Miracles Riding Academy and Ken Hall, a patient of Hospice of Northwest Ohio, enjoyed a few special moments together on the patio of the Hospice Center. Hardly a word was spoken.”
SECOND PLACE:
Gone Fishin’
Tiffany Brothers
Hospice of Dubuque
Dubuque, IA

HONORABLE MENTION:
Veterans’ Day of Honor Salute
Kelly France
MidMichigan Home Care
Midland, MI

HONORABLE MENTION:
Leaving No Stone Unturned
Timothy Nickel
Masonic Village at Elizabethtown
Elizabethtown, PA
FIRST PLACE:

Legacy of Love

Ashley Mizell
Sacred Heart Hospice
Kansas City, KS

“Anyone who knew Rita knew that she loved children. Spending time with them brought her so much joy and happiness. She lived for her 16 great grandchildren, seen here with her youngest, Bentley. Love from her family was truly the best medicine; this love was the legacy she left.”
Photography – Young People Category

SECOND PLACE:
With a Strum and a Song
Audrey Waters
MJHS Hospice and Palliative Care
New York, NY

HONORABLE MENTION:
Snuggled in a Blanket of Love
John Anglim
HopeWest
Grand Junction, CO

HONORABLE MENTION:
Compassion in Action Through Eryn’s Eyes
Alain McLaughlin
Hospice of the Valley
San Jose, CA
FIRST PLACE:
The Heart of Hospice

Laura Blumenstein
Passages Hospice
Lisle, IL

“As a hospice nurse, I care for each patient’s and family’s emotional status. I am always in action – caring for my patients with tasks such as charting, vitals, and physical assessment. But the best part of my job is living the hospice philosophy of hope, compassion, and heart in everything I do.”
SECOND PLACE:

Petals of Grief

Criss East
Evergreen Health Hospice and Palliative Care
Kirkland, WA

HONORABLE MENTION:

Web of Love

Ashley Belue
Passages Hospice
Lisle, IL

HONORABLE MENTION:

Trailing Vines of Hope

Wanda Chiles
Hospice of the Bluegrass
Cynthiana, KY
Social Media Videos

FIRST PLACE:

The Power of Community

HopeWest, Grand Junction, CO

“This video showcases the dedication of our talented staff, generous donors and tireless volunteers who impact those we love every day. Together, we are profoundly changing the lives of those experiencing serious illness and grief – one family at a time.”
Social Media Videos

SECOND PLACE:
Supporting Patients with Developmental Disabilities
Hospice of the North Shore & Greater Boston
Danvers, MA

THIRD PLACE:
Heart ‘n Home, I Am the Difference
Heart ‘n Home Hospice & Palliative Care LLC
Fruitland, ID

In honor of the families who so graciously and bravely shared their personal experience — teaching others about the comfort, love, and respect of hospice — we would like to recognize the following videos...

HONORABLE MENTION:
Patient Care: The Miller McNeil Woodruff Story
Circle of Life Hospice
Bentonville, AR

HONORABLE MENTION:
Jorie’s Story: A Mother’s Love
BJC Hospice
St. Louis, MO
Does Your Patient Admission Packet Include Everything It Should?

The patient admission packet should be given to your patients and their family or caregivers at the first care visit. While hospices may include items of their choice, the packet should also include several must-haves:

- Informed Consent form
- Notice of Patient Privacy (9/23/13 edition). (See August 2013 NewsLine for important changes that impact this form.)
- Notice of Patient Rights and Responsibilities (see CoP §418.52(c) for specifics)
- Advance Directive information
- Information about Medicare-covered hospice services, including how drugs will be covered for the terminal illness and related conditions
- Information about the scope of services that the hospice will provide and specific limitations on those services
- Material about the patient’s financial liability for any services
- The hospice’s contact information — during regular hours and after hours
- How to register a complaint with the hospice as well as the hotline of your state survey agency.

While not required, it is wise to also include:

- Explanation that all services related to the terminal illness or related conditions must be approved by the hospice provider or the patient will be financially liable for those services. (This is stated in the CMS Medicare Hospice Benefits booklet, 8/13 edition).
- List of contracted hospitals/facilities, and an explanation of how a hospice patient is admitted to a hospital and the hospice’s responsibility
- Explanation of how hospice services will appear on the Medicare Summary Notice.

Be sure to review your patient admission packet on a regular basis to be certain all necessary information is included and current.

Have regulatory or compliance questions? As an NHPCO member, you can direct your questions to regulatory@nhpco.org. (It’s one of the valuable benefits of membership!)
NHPCO’s Webinars provide cutting-edge education, ensuring you provide the highest quality of care.

Develop fresh insights, pioneering practices, and successful strategies while earning valuable continuing education/medical education credit! Attend live or purchase MP3s* for your library.

*CE/CME credit is available only for participation in live Webinars.

For more information about our 2014 Webinar schedule, visit www.nhpco.org/webinar.

Save the Date: NHPCO’s 15th Clinical Team Conference and Pediatric Intensive in Nashville, Tennessee!

Preconference Seminars: October 25-26, 2014
Main Conference: October 27-29, 2014

Keep pace with evidence-based practice, interdisciplinary care and medical, clinical, psychosocial, spiritual and bereavement best practices. Invest in your professional development and the future of your practice!

Visit www.nhpco.org/conferences for additional information.

End-of-Life Education Online (E-OL) is a convenient and affordable online learning experience.

NHPCO’s E-OL courses in clinical, interdisciplinary, psychosocial, spiritual, hospice regulatory and leadership topics are available 24/7. Regardless of budget size, access to each course and CE/CME credit (as applicable) is provided for one low cost.

To view a list of current courses, please visit www.nhpco.org/eol.
Videos Worth Watching

Intrepid walker and hospice champion, Colin Skinner, has walked across the U.S. twice, and New Zealand and Great Britain several times — all to raise awareness of hospice! While many members may have followed his most recent adventure on the National Hospice Foundation blog, Colin has now created two videos so you can hear from him firsthand. In Part 1 of the video, he talks about his early motivations for his walks, and in Part 2 he discusses the practicalities of being on the road, some of his more ‘interesting adventures,’ and the immense support he received along the way. Watch Part 1 and Part 2 now.