

# HOSPICE Management ADVISOR

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## Schiavo case highlights need for advance planning education

*Use this opportunity to correct misconceptions about hospice*

**P**inellas Park, FL, a suburban enclave nestled between Tampa Bay and the warm waters of the Gulf of Mexico, has become the epicenter of the debate over euthanasia. At the height of the drama that unfolded in October, protesters on both sides of the debate stood outside Woodside Hospice and weighed in on whether relatives and health care providers should be allowed to remove a feeding tube from one of its patients — an action that would ultimately lead to her death.

Inside the hospice, 39-year-old Terri Schiavo, who has been in a persistent vegetative state since she suffered a heart attack in 1990 and is thus likely unaware of the controversy swirling around her, continued to be cared for like the other patients staying in the inpatient hospice facility.

“Our main objective through all this was to keep our focus on the patient and family,” says **Louise Cleary**, public relations and marketing director for Woodside Hospice.

It would have been easy, perhaps understandable, if hospice officials and employees found themselves overwhelmed by attention, both good and bad. The Schiavo story ran nationally from the time Terri's husband, Michael Schiavo, won the right to remove the feeding tube that was keeping her alive to the moment Florida Gov. Jeb Bush and the state legislature intervened and passed “Terri's Law” to have the tube re-inserted.

The frenzy is expected to pick up once the Florida State Supreme Court rules on whether Bush's and the legislature's actions were constitutional.

Almost lost in the salvos lobbed by right-to-life activists, including many from the anti-abortion movement, and proponents of euthanasia, such as End-of-Life Choices (formerly the Hemlock Society), was any message about the importance of preparing advance care directives.

But among the letters to the editors of the two local papers — the *Tampa Tribune* and the *St. Petersburg Times* — were those that told how

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an ounce of prevention could have kept the Schiavo case from becoming so controversial.

The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, used the opportunity to remind people to prepare living wills or advance directives.

"The NHPCO urges everyone, regardless of their age, to take this opportunity to discuss their end-of-life wishes with family members and put it in writing with advance directives," the trade group said in a written statement. "The National Hospice Foundation, NHPCO's development arm, has developed a number of brochures to help families begin these important discussions."

While the message was aimed at the general public, industry leaders also hoped hospices would use the Schiavo case as a soapbox to remind people in their own communities to put their wishes in writing and share those wishes with loved ones.

"We've seen hospices pick up the ball and run

with it," says **Jon Radulovic**, senior communications officer for NHPCO.

"As the very public and tragic battle surrounding Terri Schiavo's life has played out in the national media, I suspect many Americans have been asking themselves a troubling question: 'If I were in her position, what would I want? And, perhaps even more importantly, would anyone know what I want?'" **Donald Schumacher**, president of NHPCO wrote in an op-ed piece.

"We need to start asking these questions out loud, in conversations between husbands and wives, adult children and their elderly parents, caregivers and friends and loved ones of all kinds. Indeed, if there is any good to come out of the firestorm over Ms. Schiavo's case, let it be increased awareness of the need for and use of 'advance directives' — the umbrella term for documents that spell out in writing how you wish to spend your final days."

Since the case was publicized, Partnership for Caring (PFC), the only consumer group to offer free advance directive documents for all 50 states, has fielded thousands of requests for living wills and for advice on how to complete the documents.

PFC reported that in the weeks surrounding coverage of the Schiavo case, the number of advance directives downloaded daily from its web site increased from an average of 150 to over 1,000. And the number of calls to its toll-free hotline that counsels consumers on how to complete the forms jumped from 20 to 150 a day.

"Regardless of the countless parties weighing in on the Schiavo controversy, the essence of the matter is that this terrible family tragedy was preventable," says a position statement prepared by the Last Acts Partnership.

In 2001, *Hospice Management Advisor* published an article offering guidance to its readers on the importance of advance care directives. The article stressed the importance of educating the public, and experts advised that the time to educate people about advance directives is not in the hospital before a procedure, but in the physician's office while they are healthy or in a lawyer's office while preparing their will. At that time, people should receive literature that explains such intensive care treatments as cardiopulmonary resuscitation, ventilators, and artificial nutrition and hydration.

The topic of dying is a complicated subject. Perceptions of end-of-life care vary from one person to the next, one religion or culture to another. There is no one-size-fits-all approach to getting the discussion rolling, experts say.

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Editor: **Eric Resultan**, (770) 329-9684, (eric\_resultan@msn.com).

Vice President/Group Publisher: **Donald R. Johnston**, (404) 262-5439, (don.johnston@thomson.com).

Editorial Group Head: **Glen Harris**, (404) 262-5461, (glen.harris@thomson.com).

Managing Editor: **Robin Mason**, (404) 262-5517, (robin.mason@thomson.com).

Production Editor: **Brent Winter**.

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### Editorial Questions

For questions or comments, call **Glen Harris** at (404) 262-5461.

## Advance directives make choices clear

Hospices should work with their medical practice partners to develop a process in which patients are informed early about advance care directives. Experts suggest that when people create an advance directive, they should provide more detailed information than is required by state law and expand on their wishes regarding how matters should be handled at the time of their death.

In the advance directive, patients should clarify their beliefs on various medical procedures, attitudes about organ donation, views on health, and thoughts about independence and control.

The Journal of the American Society of Certified Life Underwriters provides guidelines

to help people make end-of-life decisions in four situations:

- if the patient were in a coma or persistent vegetative state;
- if the patient were in a coma and might survive;
- if the patient had brain damage;
- if the patient had brain damage and a terminal illness vs. no terminal illness.

In each situation, several medical treatment options were offered, such as CPR, a ventilator, nutrition and hydration, surgery, chemotherapy, invasive tests, blood products, and pain medicine. Under each treatment option, people could mark one of the following four options:

- I would want.
- I want treatment tried; if no clear improvement, stop.
- I am undecided.
- I don't want. ■

People can benefit from examining their feelings about death before they are confronted with it. Everyone should explore their attitudes toward death and how denial, anger, spiritual crisis, or acceptance can play a role.

Hospices take a variety of approaches to death education. For example, information about what to expect during a terminal illness and near death should be available so caregivers will understand that when their loved one becomes withdrawn or disoriented, that is part of the natural process of dying.

Other programs help people access their own resources. For example, while a daughter may not have lost her mother to breast cancer before, she has dealt with other losses, challenges, and crises. She can take what she has learned from these past experiences and apply it to the current situation.

For example, keeping a journal, writing poetry, and taking long walks may have helped this person adjust to her divorce. Those learned coping skills may be used to deal with her current situation.

Another way to promote advance care planning is to provide supportive counseling for patients and family members in the medical office setting where life-limiting illnesses are diagnosed. It is common for family members to misunderstand the concept of withdrawing life support. Their image usually is one of pulling a

plug, as opposed to decreasing ventilator support gradually, accompanied by measures to keep the patient comfortable with medication.

### ***Battling misconceptions***

In addition to raising awareness about advance care directives, the Schiavo case has potential both to contribute to public misunderstanding of the hospice mission and to provide an opportunity to educate the public about hospice care.

"Unfortunately, hospice got dragged into the story," Radulovic says. "Some hospices got calls, and we got a lot of calls. There were misconceptions about hospice, that euthanasia and hospice were related."

Recognizing the legal complexity and emotional breadth of the Schiavo case, the NHPCO used the stage to clarify the role of hospice in end-of-life care.

"Hospice does not make decisions for patients or families, nor sit in judgement of their choices," the NHPCO said in a written statement. "Instead, hospice provides information on care options and compassionately carries out those decisions with respect for their wishes and the laws of the land. This enduring focus on the patient's wishes and the provision of interdisciplinary care are the cornerstone of hospice."

The NHPCO also used the opportunity to distinguish inpatient hospice from the more common

# What can hospice offer to PACE sites?

*Philosophies similar; opportunities may be limited*

By **Larry Beresford**

One of the more intriguing prospects for hospice's participation in a broader continuum of palliative or end-of-life care is collaboration with PACE (Program of All-Inclusive Care for the Elderly) sites.

PACE is the federal program created to clone San Francisco's legendary On Lok Senior Health Services program. The possibilities of working with PACE sites, along with some real-world examples, were highlighted at the recent conference of the Alexandria, VA-based National Hospice and Palliative Care Organization, held in September in Phoenix.

PACE dissemination nationwide has been disappointingly slow, despite consistent federal encouragement, elevation in 1997 from demonstration to permanent status under Medicare and Medicaid, and additional legislation passed in 2000 to expand its opportunities for growth. Today there are 37 operational PACE sites across the country, with others in various stages of development. It's projected that there will be between 50 and 100 functioning sites within five years, according to **Shawn Bloom**, executive director of the National PACE Association in Washington, DC.

### ***PACE and hospice: Parallel tracks***

Presentations at the Phoenix conference emphasized the complementary philosophies of comprehensive, coordinated end-of-life care practiced by hospice and PACE, which developed on parallel tracks in the early 1980s. If anything, PACE is even more holistic, coordinated, and team-oriented than hospice, with a determination to maximize independence and quality of life for the frailest elderly participants.

PACE has an impressive track record of keeping such clients in their own homes and communities and out of hospitals, emergency rooms, or

home hospice. "Ms. Schiavo is currently receiving care in a hospice residence in Pinellas Park, FL," the NHPCO statement continued. "While approximately 80% of hospice care is provided in the home, many hospice providers have residences for patients who cannot be cared for in their own homes. Residential hospice programs provide compassionate hospice and palliative care in a home-like setting 24 hours a day, seven days a week. Neither the specific hospice or NHPCO is involved in the legal proceedings associated with the patient or the decisions to remove the feeding tube. Hospice provides state-of-the-art medical care reflecting the highest standards of practice and compassion. Hospice also offers bereavement services for family members." ■

## NHPCO offers educational material

Recent media attention has focused on a case in Florida regarding litigation and care of Terri Schiavo, a patient receiving care in a hospice facility. In some of these reports, the role of hospice has been unclear.

In recognition of the legal complexity and emotional breadth of the Schiavo case, the Alexandria, VA-based National Hospice and Palliative Care Organization (NHPCO), and the NHPCO's development arm, the National Hospice Foundation (NHF), have provided the documents below on the NHPCO web site to offer further insight into this case and help those interested in information about advance care planning:

- NHF brochure, "Communicating Your End of Life Wishes";
- NHF brochure, "Let's Start Talking";
- NHPCO position paper clarifying the role of hospice in the Schiavo case (10/15/03);
- Op-ed from J. Donald Schumacher, PsyD;
- Op-ed from David Casarett, MD;
- talking points;
- An article from the *Washington Post* (10/23/03) that provides information on the difference between a persistent vegetative state and a coma, and the experience of death in such cases. ■

nursing homes. Nationally, about 20% of PACE enrollees die each year, so the program has plenty of experience in providing end-of-life care.

“Philosophically, PACE and hospice could be wonderful partners, but realistically, what are the opportunities for this actually happening on a widespread basis?” Bloom asks. Other observers see the potential for innovative collaborations, although on a fairly limited scale.

### ***What is On Lok?***

The PACE prototype, On Lok (Cantonese for “peaceful, happy abode”), began in San Francisco’s Chinatown in 1971 as an adult day health center. Home care services were added in 1975, federal demonstration project status in 1978, and a unique Medicare/Medicaid waiver in 1983, making On Lok true one-stop shopping for all medical, rehabilitative, social, and supportive services needed by the frail elders under its care.

Today On Lok serves a culturally diverse caseload of nearly 1,000 clients, with an average age of 82. Based on its long success at keeping them in the community, the federal government began supporting research on the model and how to replicate it, leading to authorizing legislation for PACE, which passed in 1987 and 1990.

Clients eligible for PACE must be 55 or older, residents of the site’s service area, and certified by the state Medicaid agency as frail enough to need nursing home-level care. In exchange for providing and coordinating a comprehensive range of acute care, long-term care, and supportive services (including all Medicare- and Medicaid-covered benefits), the PACE site receives monthly capitated payment from Medicare and Medicaid (current combined rate is about \$3,800, regionally adjusted). Most PACE clients qualify for both Medicare and Medicaid, but a smaller proportion pays out-of-pocket for either or both components.

Adult day care is an essential centerpiece of PACE sites, and primary medical care is provided by physicians on staff. The structure is so comprehensive and coordinated that it can be difficult to pull together all of the pieces required for a successful PACE application, which is reflected in the small number of operational sites.

The components of a successful PACE site include consumer advisory committees, geriatric-experienced staff in a number of disciplines, dental care, and demonstrable financial stability and reserves. It is often said that the driver who brings participants to the PACE center every day is one

of the most important members of the team and a key informant regarding what’s going on in the client’s life.

Privately funded and federal demonstration grants are now trying to encourage greater participation by for-profit and rural PACE sites as well as statewide coordinating efforts. The current crisis in state Medicaid budgets is a major barrier to PACE expansion, Bloom says, but in time could encourage wider use of the demonstrably cost-effective program.

### ***How PACE can work with hospice***

There are several ways for hospices to work with PACE sites, he notes. However, it is not realistic for hospices to expect PACE sites to refer their dying patients on a widespread basis for hospice’s all-inclusive approach and per diem reimbursement. Such referrals would require the PACE site either to disenroll them from PACE or else directly pay the hospice’s per diem under contract out of its capitated rate.

PACE participants are enrolled, on average, two or more years prior to their deaths, and by the time they have a prognosis of six months or less to live, they have established relationships with the PACE team and their primary care physician, who have confidence in their ability to manage the terminal phase of care, as well.

Recent Medicare memorandums have confirmed that PACE’s care management responsibility includes end-of-life care, but purchasing specialized palliative care consultation services from a certified hospice would be permitted under Medicare rules.

Referrals from PACE for hospice care would be the occasional cases where the patient’s need could not be met any other way, where hospice’s end-of-life expertise was particularly needed, or at times of peak capacity. A better bet for the hospice might be to work with a new PACE site with less end-of-life expertise and resources. More promising is for the hospice to offer unbundled palliative care or bereavement services as needed by the PACE team, Bloom says. A final option is for the hospice to become a comprehensive PACE site. Particularly in rural areas where PACE has not been able to get a foothold, the hospice program already may have the best infrastructure for comprehensive care of isolated frail elders.

“If I were a hospice, I would focus on bringing to bear a set of consultative services in palliative and end-of-life care that can be provided to PACE

on an a la carte basis — and be sincere about it,” rather than trying to encourage the PACE site to disenroll its patients and refer them for hospice care, Bloom says. Current hospice/PACE collaborations include the following:

- San Diego Hospice is closely involved in the development of a new PACE site proposal by St. Paul’s Senior Homes and Services in San Diego, with plans for the hospice to be a major subcontractor for pieces of the PACE continuum, including medical services provided by its staff physicians.

- In Cleveland, Hospice of the Western Reserve has provided palliative care services to the clients of Concordia Care, an operational PACE site, since 1999. Their contract covers all of the members of the hospice’s palliative care team, as well as its inpatient, respite, and residential levels of care, but most referrals from Concordia are for the hospice’s palliative care nurse, who currently carries a caseload of 22 PACE enrollees.

- Other examples of PACE sites contracting with local hospices for palliative care consultation services include Providence Elder Place in Seattle and ESP North Shore in Boston.

- Hope Hospice and Palliative Care in Fort Myers, FL, is interested in developing its own PACE site, but needs enabling state legislation in order to go forward.

- Midland Hospice in Topeka, KS, which has operated an adult day care program for both hospice and non-hospice clients since 1993, is now developing a proposal to the Centers for Medicare & Medicaid Services to become a PACE provider in its largely rural service area.

“PACE is integrated even beyond what we do in hospice,” Midland Hospice executive director **Karren Weichert** says. “It’s a continuous process of assessment, treatment planning, service provision and monitoring.” Hospices should be involved in PACE development, she says, “because it is happening, and it is working. PACE is a good program.”

Is collaboration between hospices and PACE sites viable? “You have to go back to the question: Can the mission of hospice support it?” notes **Judy Bartlett** of Hospice of the Western Reserve in Cleveland. “It’s not a money-making endeavor for hospice to work with PACE. But if the hospice’s mission is to provide excellence in palliative care to the entire community, and its core values are aligned with the PACE program,” then collaboration could make a lot of sense.

On Lok, the flagship PACE provider, refers

about 10 terminally ill clients per year to local hospices out of its caseload of nearly 1,000. In most cases, the On Lok team is fully committed and qualified to care for clients dying at home, says On Lok’s executive director, **Jennie Chin-Hansen**.

“Hospice is well known for its synchronized, compassionate care. I think that’s also what we offer. We also become part of their family, but at an earlier stage of the illness.” The richness of the relationship between the client and the team is what enables On Lok to manage its patients’ care up to the point of death, she explains. “We’re not about unnecessary heroics. On Lok was built from early on with the commitment to be there for the whole nine yards. And most of our clients choose a comfort-care approach.”

The team makes it a priority to assess and establish the client’s care preferences and lifestyle choices right from the beginning. “We bring in the family and try to do some preventive engagement, such as establishing who’s going to be the decision-maker or have durable power of attorney, before the point of crisis,” Chin-Hansen reports. “We may not be quite as specialized as hospice, but it seems like the core services are captured by this approach,” including the concept of dignity and a focus on comfort care and pain management. ■

## Put yourself in MD’s shoes before asking for referrals

*Develop concise message to describe your services*

**W**ill that new supply of coffee mugs, calendars, note pads, and pens engraved with your hospice’s name and phone number make physicians or their nurses refer to you? Probably not, according to experts.

“I don’t need another coffee mug,” says **M. Tray Dunaway**, MD, FACS, CSP, a physician and author of *Doctors are from Jupiter and Compliance is from a Galaxy Far ... Far ... Away* and *Pocket Guide to Clinical Coding*. “I need a home health agency that will be a partner in my success and save me time and make me money. Most home health marketing people are health care people, and they don’t always look at what they are selling from the buyer’s perspective,” Dunaway says.

When you are trying to establish a relationship with a physician, it is the physician who is the customer, so it is important to focus upon the issues that are important to the physician and the physician's practice, he adds. "Saving time and making money are important," he reiterates.

### ***Make communication easy***

If your agency has a mechanism that makes referrals simple and getting orders signed easy for the physician, then you are saving time for the physician, Dunaway adds. He points out that agencies that send orders for signature through the mail with postage-paid return envelopes actually have been a financial boon for him, as he collects all of the orders, returns them in one envelope, and saves the stamps from every other envelope. It is OK, and preferable, to include more than one order for signature in an envelope, he explains.

The staff at Community Home Health & Hospice in Longview, WA, still mail orders to physicians, but have been able to greatly improve response time and have made it easier for the physician to read the orders, says **Terry Skrentny**, BSW, RN, clinical information systems and medical records director at the agency. "We used to have 40% of orders take 30 or more days for signature. Now, we receive 85% to 90% of the orders within two weeks," she says.

Skrentny's agency automated with a software system that gives field nurses laptops on which they enter the visit information and transmit the data to the office. Orders and 485s are automatically printed in the office for staff members to mail to physicians. "Prior to automation, we would hand-write the orders, and we often had physicians say they couldn't read what was written," she explains. "With automation, the orders are legible, and the physician doesn't have to spend time trying to decipher handwriting," Skrentny adds.

Some of Skrentny's physicians prefer to have orders faxed to them for signature, and her software has that capability, she says. "We still mail 90% of the orders," she notes. Although her agency is not yet using the capability to send and receive electronic signatures, it is a possibility for the future if enough physicians will benefit, Skrentny adds.

While home health agencies cannot bill for physician oversight of a home health patient for the physician, provide resources that can be

used to make sure the physician is reimbursed for his or her time, Dunaway says. Providing booklets that explain billing codes or referring physicians to web sites that offer guidance will demonstrate that you understand the financial implications as they relate to a physician's office, he says.

Not only does a physician expect you to provide quality care to his or her patients, but a hospice representative also should be able to describe services that differentiate your hospice from others in the area, Dunaway says. "If you tell me that you are better than other agencies, I immediately doubt it," he says. "Instead, tell me about your cardiac rehab program, your cutting-edge wound-care program, or your specialized staff for diabetes care. If I see that your agency is able to handle the tough patients, I will know that you can handle routine patients," Dunaway adds.

A home health agency is an extension of the physician's practice in the patient's home, he explains. Not only does the physician want to be assured that the staff is composed of quality nurses, but he or she also wants to know that the nurses will support the physician in front of the patient, he says.

"For example, if the nurse notices an error in the medication order, instead of saying that it appears the doctor made a mistake, the nurse should say that with all new, cutting-edge medications we have available, he or she just wants to double-check the dose," Dunaway suggests. "Then, the nurse can call me and point out that one of the new medications may interact with another, and I have a chance to prescribe another medication or change the dose. In this instance, the nurse enabled me to fix my mistake without compromising my patient's trust in me," he adds.

### ***Focus on top referral sources***

"Everyone likes closing a sale, but what does it mean if you visit 100 doctors and only 10 of them are likely to refer patients to your agency?" asks Dunaway. "Know your buyer; know exactly who is sending you patients," he says. This not only means knowing who your top referral sources might be, such as specific physician practices or hospitals, but also knowing the specific people in those organizations, he explains. Be sure you focus your efforts on the people most likely to send you business, Dunaway says.

Skrentny agrees. "We have 3,000 physicians in our database for the geographic area we serve,

but 75% of our referrals come from 300 of those physicians.”

As you focus on your top referral sources, remember that you only get about two minutes to sell the physician on developing a relationship with your agency, Dunaway points out. “Have your positioning statement ready and explain how your services will save the physician time, provide excellent care, and make his or her life less stressful,” he suggests. ■

## ‘Making it personal’ improves patient care

*Personal histories increase patient satisfaction*

**S**heila Brune, RN, CPHQ, CPUR, says the quality of direct patient care is the most important predictor of patient satisfaction. In the past few years, Brune, CMC director of Utilization Management/Living History Program at Great River Medical Center in West Burlington, IA, has proved her point emphatically with an innovative program inspired by her desire to create closer connections with patients.

The Living History program involves the creation of “a living, breathing chronicle of the patient’s nonmedical history.” The intent of the history is to empower caregivers to deliver care to the heart and soul of the patient, Brune says.

Brune first began thinking about the program about two years ago, when her CEO returned from a training session led by Quint Studer of The Studer Group. “What impacted me were two issues,” she recalls. “The first was a question: Are you part of the problem or part of the solution? The second was the assertion that you’ll be judged by the people you touch.”

The task she decided to undertake didn’t even fit her job description. “I was director of utilization management; people always said I was the ‘dollars-and-days dame,’” she notes. “But at my heart, I am a nurse.”

Brune was aware that often patients would be with the hospital for a long time, and then one day she would by chance read their obituaries.

“I realized that there was a lot more to those people than we had thought,” she explains. “I wanted to explore how we could get that information before they died. I like telling patients

that I want to know what they do when they’re not here.”

It’s all well and good to be curious about a patient’s personal history, but why is it important from a quality standpoint? Why is it important to “deliver care to the heart and soul of the patient?”

“There are lots of reasons,” Brune says. “It makes the patient feel more valued — that you are thinking about them not as a number, but as a person. What people want most is to feel valued and to be listened to. Also, I believe if you improve the patient/caregiver relationship, not only does the patient feel better, but the caregiver does, too. It increases their satisfaction with their job.”

She recalls comments from nurses like: “I can’t believe what you did for me with this story. We found connections that went way back.”

Brune cites a number of occasions where patients had actually worked with relatives of caregivers, and, in at least one case, a nurse found out much more about a relative who had passed away than she ever would have known had she not connected with the patient.

This is one of the three different ways in which caregivers are encouraged to build bridges with patients. They are:

- **Real connections:** “I know your daughter.”
- **Compassionate connections:** “You have been through a lot in your life.”
- **Scripted connections:** “I see you like to do woodworking. What do you like to make?”

Brune decided to build the program through story writers — special employees selected to get the patients’ stories.

She also determined that, initially, stories would focus on chronically ill patients with diagnoses that caused multiple admissions, i.e., seriously ill, terminally ill, or very elderly patients, or patients on dialysis or in hospice care. “We went through the DRGs and picked longer-stay, high-volume, high-risk patients, but now we go more on our gut,” Brune says. “Age is first, because the extreme elderly have fascinating stories. We also look at diagnoses — cancer, stroke/CVA, COPD, and CHF, as well as surgicals who will be here longer, like hips, knees, and colonoscopies.

“Now, we will also take referrals,” she adds. In the beginning, however, she had to spread the word. “I just went out and talked to everyone, in every department,” she recalls.

She started with the CEO, who said yes; then, the senior management team, who said, “Make

it happen," then to the middle managers, and then to staff meetings. "We also went out into the community, through TV and radio," Brune says.

"And we solicited people from each department to be story writers; almost every department was represented." This also helped involve employees who would not normally come in contact with patients. "Clinical information is not often shared with librarians," Brune notes.

In the beginning, Brune picked the story writers. "Now, I let them pick me," she says. If they show interest, their managers must sign off, because they spend an average of two hours on each assignment. The story writer's commitment is for one story a week.

Once the selection has been approved, there is a one-day training session, facilitated by an educator, a social worker, a recreation therapist, a journalist/editorial review writer, and Brune. Following that, the assignments are made, and the story writers visit the patients, who tell their personal stories.

Interestingly, the profile of story writers has changed over the years. "We only have two of the original story writers left," Brune says.

"The people I first picked were outwardly, openly enthusiastic, and those criteria may not have worked; maybe they were just big talkers, but short on action. My best story writers have been the 'sleepers' — those people who quietly work every day," she explains.

### ***'Always read the Living History'***

The Living Histories are used and shared in a number of ways. They are presented in a visual depiction known as a bridge poster — milestone events and family facts are depicted, centered around a logo of a bridge — for the patient's room. The Living History itself is placed as the first item on the patient's chart.

There is an absolute expectation that all of the patient's caregivers will read the history. "One of our deals with our CEO is 'non-negotiables,'" Brune explains. "We say things like, always wear your name tag, always lead people who are lost to the department they need, and always read the Living History."

The copy that is placed in the chart is put in a plastic sleeve protector. One copy is given to the patient, and it can be laminated if they request it. They then receive as many additional copies as they want. They also receive one bridge poster, also laminated upon request.

The stories also live on through Meditech, the facility's computerized record medical system. "I save the stories to a Word file and then enter them into the Meditech screen, so you have a record of the patient's story and who wrote it," Brune says.

To date, 1,700 stories have been written. "We need more story writers," she says, noting that care is changing and patient satisfaction is growing. The facility's current Press, Ganey Associates satisfaction rate is more than 90%, up considerably from two years ago. "We have no reason to believe it will not continue to climb," she says.

Brune is eager to share her success story with other institutions. "We have two hospitals starting their own programs [soon], and we probably have 20 out there who have placed phone calls, have come here or are planning to come to visit," she says. ■

## **New tool evaluates care options for seniors**

*Web site educates and empowers caregivers*

Those who work with senior citizens have a new tool to help them advise their clients on appropriate care or living decisions.

CarePlanner is a web site and on-line tool to help people make decisions about care for the elderly or disabled, based on their situation and preferences. The purpose of the tool is to educate and empower caregivers to make appropriate decisions, including keeping seniors at home if possible, says **Meghan Coulehan**, MPH, research project director for CarePlanner at Clinical Tools Inc., a health care management company that developed CarePlanner through a grant from the Centers for Medicare & Medicaid Services.

The CarePlanner asks users a series of questions about the senior's age, gender, current living environment, and state of residence. It includes questions about financial issues, health status, treatments, ability to carry out activities of daily living, personal preferences (such as doing their own cooking or sharing a bedroom), and the availability and health of any caregivers.

Based on the selections, the CarePlanner creates advice reports analyzing the senior's potential for successfully living in each of seven living

and care options: hospice, home care, retirement community, continuing care community, personal care home, assisted-living facility, and nursing home.

The tool includes links to other agencies and organizations that can help in implementing the plan.

"It doesn't tell people what the best option might be. It gives them recommendations for successful placement," Coulehan says.

The CarePlanner aims to educate seniors, their families, and caregivers about community-based and home-based health care options, with an emphasis on options that provide care at home, she adds. "Most people don't know about all the resources that are available. If Mom falls and breaks her hip, the family thinks the only option is to put her in a nursing home," Coulehan says.

The tool is designed for seniors, physically disabled people with a chronic illness who need supportive services, and their caregivers, case managers, social workers, and families.

The care planning process tends to be overwhelming, Coulehan comments.

"A lot of times, people become caregivers because of a sudden event. They know nothing about caregiving options or making arrangements, and it's dumped on them all at once," she adds.

For more information, see the CarePlanner web site at [www.careplanner.org](http://www.careplanner.org). ■



## CMS unveils cyber-help to assist providers

Medicare officials are hoping a more effective web site will assist health care providers in getting the information they need to better serve beneficiaries.

An expanded and improved site has been unveiled by officials at the Centers for Medicare & Medicaid Services (CMS). Physicians and other practitioners will find most of the information they

are seeking by clicking on the Professionals tab at the top of the CMS page, according to officials.

"We want doctors, hospitals, and other health care providers to know that valuable, updated Medicare information is available to them at a single, easy-to-find web site," said CMS administrator **Tom Scully**. "These web pages also remain open to any beneficiary, family member, or others who want to be more knowledgeable about specific areas of the Medicare program." Eventually, CMS will create individual web pages specific to all Medicare providers.

Pages currently under development include one dedicated to durable medical equipment, a CMS spokesman says. Additional pages under construction include sites for ambulatory surgical centers, federally qualified health centers, hospice, rural health, and skilled nursing facilities, the spokesman added.

Individualized pages contain links to information related to specialized areas, such as federal regulations and notices, program memorandums, training and educational activities, and answers to frequently asked questions.

New pages now available include the following, all having the common directory [www.cms.hhs.gov/](http://www.cms.hhs.gov/):

- Ambulance services: [suppliers/ambulance](#)
- Drugs: [providers/drugs](#)
- Physicians: [physicians](#)
- Hospitals: [providers/hospital.asp](#)
- Acute inpatient: [providers/hipps/](#)
- Outpatient PPS: [providers/hopps/](#)
- Critical access hospitals: [medicaid/survey-cert/cah.asp](#)
- Long-term care hospitals: [providers/longterm/](#)
- Inpatient rehabilitation facilities: [providers/irfpps/](#)
- Home health agencies: [providers/hha](#) ▼

## Nursing group offers hospice grant

The American Association of Critical Care Nursing (AACN) is offering a one-time grant titled "Initiating Hospice Care in Critical Care." The deadline for proposals is Feb. 15, 2004.

The grant's purpose is studying end-of-life or palliative care outcomes. While reviewers will

allow a broader range of topics, special consideration will be given to projects that focus on implementing palliative or hospice care in the intensive care unit.

Other topics may include:

- bereavement (e.g., family, patient, or caregiver);
- communication issues (verbal, nonverbal, or written);
- caregiver needs (e.g., stress, education, emotional support);
- symptom management (e.g., nausea, vomiting, pain, anxiety, skin breakdown, etc.);
- advance directives (e.g., staff/patient education, development, ethical issues);
- life support withdrawal (ethical/legal concerns, clinical protocols).

Eligible projects may focus on patients of any age, patient education, staff development, outcomes evaluation, and small clinical research studies. Funds may be used to cover direct project expenses, small equipment, or supplies such as computer software but not salaries or institutional overhead.

Applicants must be current members of AACN. Principal investigators currently funded by AACN are ineligible for this grant during the lifetime of their original project or grant. For further information contact AACN at (800) 899-2226 or [info@aacn.org](mailto:info@aacn.org). ▼

## NHS spends £50M more on terminal cancer care

Allocation of an additional £50 million across the United Kingdom to improve care for terminal cancer patients has been made by a national partnership group that included representatives from the National Health Service (NHS) and voluntary organizations.

The funding represents an increase of about 40% in NHS funding for specialist cancer care above 2000 levels for such care.

The expanded funds will go to:

- a support and training program in palliative care for nurses caring for patients in the community, community hospitals, and care homes;
- 70 additional consultants in palliative medicine to give more people access to relief from their pain;

- 162 more clinical nurse specialists to support patients and families in hospitals, care homes, and at home;

- additional nurses to provide practical care to patients and allow more people to spend their last days at home;

- 86 more hospice beds to give patients and families the extra support they need.

“This money will make a real difference for patients,” said **Eve Richardson**, chief executive of the National Council for Hospice and Specialist Palliative Care Services. “The National Council has been delighted with the collaborative approach taken by the Department of Health in working with the council and its voluntary sector and NHS partners in the allocation of these funds.”

**Richard Hillier**, MD, consultant at St. Joseph’s Hospice in London, said the £50 million “is unprecedented and, to me, undreamed of. Targeted funding to bring good palliative care to all patients and families who need it, wherever they are, and to support hospices is precisely what is wanted.”

The national partnership group, under the chairmanship of National Cancer Director Mike Richards, includes representatives from the NHS at all levels and from a wide range of voluntary sector organizations. Those include, in addition to Richardson’s and Hillier’s organizations, the Independent Hospice Representative Committee; Help the Hospices; Macmillan Cancer Relief; Marie Curie Cancer Care; Trinity Hospice London; St. Catherine’s Specialist Palliative Care Center; West Sussex, Torbay and South Devon Hospice; and Compton Hospice, Wolverhampton. ▼

## CMS begins effort to stop wheelchair benefit abuse

The Centers for Medicare & Medicaid Services (CMS) announced an initiative to curb abuse of the Medicare program by unscrupulous providers of power wheelchairs and other power mobility products who prey on Medicare beneficiaries.

At the same time, the Department of Health and Human Services Office of Inspector General (OIG) said it is investigating the proliferation of durable medical equipment (DME) fraud cases involving inflated billings to Medicare, charges for equipment and supplies not delivered, and

the falsification of documents to qualify beneficiaries for wheelchairs and other equipment that they often did not need.

“Spending on power wheelchairs has increased nearly 450% over the last 4 years, an unprecedented growth in this benefit,” said CMS administrator **Tom Scully**. “While many of these wheelchairs are provided by ethical suppliers and go to beneficiaries in need, we know that a great number of unscrupulous suppliers are promising free wheelchairs to beneficiaries who don’t need them. We are taking immediate action to stop these scams.”

Acting Principal Deputy Inspector General **Dara Corrigan** warned Medicare beneficiaries to be suspicious of offers of “free” scooters and other enticements from unscrupulous suppliers.

CMS plans to start its nationwide clean-up campaign in Texas, where recent reports from the CMS Dallas Regional Office and a Houston newspaper have highlighted the growing and very serious financial threat that improper spending on wheelchairs poses to the Medicare program. In Harris County, TX, alone, Medicare paid for more than 31,000 power wheelchairs in 2002, compared to a little more than 3,000 power wheelchairs in 2001. HHS agencies will work with the Department of Justice in attacking the problem. ▼

## Agencies not prepared for HIPAA transaction rules

As of May 2003, only 43% of home health agencies responding to the Alexandria, VA-based American Association for Homecare’s (AAHomecare) 2003 Financial Performance Survey Report indicated they were in compliance for the Health Insurance Portability and Accountability Act (HIPAA) deadline for electronic transactions.

The annual survey of financial and management practices of home care companies is based on data from the previous year’s operations. This is the 14th Survey Report released by AAHomecare and features new sections on HIPAA IT compliance and delivery and clinical personnel efficiencies.

Key findings in the survey this year include:

- Home health companies spent an average of \$5,700 on IT compliance, with 25% of respondents spending more than \$17,000.

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- Hospital ownership of firms was 28% in 2002. In past surveys, the proportion of hospital ownership has ranged from 25% to 35%, putting this year’s results at the lower end of the range.

- In 2002, the age of overall accounts receivable averaged 83 days, which is down by 2% from the prior year. The percentage of 120-day receivables remained high at 24%.

- The 8% of participating companies that reported making an acquisition experienced an overall growth rate of 22% (up from 16% in 2001). However, their average growth rate for continuing business was 9%, closer to the industry average.

The entire study, including additional profit statistics and a wide range of industry financial data, can be purchased at the AAHomecare web site ([www.aahomecare.org](http://www.aahomecare.org)) or by calling Allison Barton-Kramer at (703) 535-1883. The cost is \$250 for AAHomecare members, \$500 for non-members. ■

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# Hospice Management Advisor

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