

HOSPICE Management ADVISOR

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America mourns, hospices respond

Bereavement experts help a nation deal with its grief

When three hijacked commercial airliners slammed into the Pentagon and the twin towers of the World Trade Center and a fourth crashed in a Pennsylvania field, killing more than 6,000 people, a nation gasped at the magnitude of the carnage. As disbelief gave way to anger and grief, few Americans were immune to a feeling of loss.

The worst act of terrorism on American soil left wives grieving for husbands, sons grieving for mothers, sisters grieving for brothers. And the mourning was not confined to New York, Washington, DC, or the hometowns of its victims. People in every state are still grieving at some level: Employees of companies based across the country weep for fallen colleagues; people cry for the heroic rescue workers who were buried trying to help those fleeing from the crumbling skyscrapers; and many mourn the loss of a nation's sense of safety. American society, it seems, has changed, leaving those in it more suspicious and fearful.

In the midst of the pain and in anticipation of the waves of grief that will follow, hospices haven't shrunk from the responsibility of helping those who have lost loved ones as well as those who have been affected indirectly, but significantly.

"I started getting calls as early as Tuesday [Sept. 11, the day of the attacks] from hospices as far away as Texas and Wisconsin," says **Kathy McMahon**, president and chief executive officer of the Hospice and Palliative Care Association of New York State in Albany. "They offered to send bereavement counselors, chaplains, and social workers."

The New York hospice trade group, the state equivalent of the Alexandria, VA-based National Hospice and Palliative Care

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Organization (NHPCO), has acted as a clearinghouse that New Yorkers can use to get in touch with bereavement experts.

“There has been a huge amount of outreach,” says McMahon. “I’m very impressed with how this community has come together.”

In addition, hospices such as the Hospice of Orange and Sullivan Counties set up grief centers at its suburban New York City offices in Middletown and Newburgh. “We have gotten a number of calls from schools wondering if they are saying the right things to their students, and from hospitals seeking grief and bereavement inservice training for their employees and families of victims,” says **Kathi Webber**, community relations director for the hospice.

Other hospice involvement included grief and bereavement care for families of New York City rescue workers and police officers who were killed or missing as a result of the massive collapse of both towers.

But with the impact of the tragedy being felt nationwide, there are many who can benefit from grief and bereavement care. Americans who sat in front of their television sets and watched terrorism unfold only to have the same images repeated over and over again are also searching for answers and pondering unfamiliar emotions.

NHPCO calls for hospices to help out

The NHPCO reacted quickly, urging its members to volunteer their services where needed. On the afternoon following the attacks, NHPCO Board Chairwoman Rafael Sciuillo issued a member alert asking hospices with bereavement or other counseling staff who could assist with the situation to contact hospice organizations in states near the crash sites.

Citing “respect for the magnitude of loss following Tuesday’s national tragedy, and based on the need for hospice personnel to provide bereavement leadership and support in their own communities,” the executive committee of NHPCO postponed its 16th Management and Leadership Conference, which was scheduled for Sept. 24-26 in Arlington, VA. NHPCO hopes to reschedule this event for early December.

The NHPCO’s call underscores the importance of hospices addressing the tragedy’s effects in their own communities. New York is an economic hub that attracts not only visitors, but also national and multinational corporations that have offices in the city’s financial center. With that in mind, hospices

should offer their services to employers in their communities that have ties to companies that lost employees inside the World Trade Center.

To provide hospices with resources to use in their own communities, the NHPCO has posted guides to help employers understand workplace grief. Hospices working with companies should help them understand the following:

- **The grieving process.** Feelings and symptoms of grief can take weeks, months, and even years to manifest and evolve. This underscores the importance for a sustained program, rather than one that dissipates as memory of the events fade.

Equally important is educating workers that grief and mourning occur individually and that healing cannot be expected to follow a timetable. In time, however, the emotions will ease. Workers should be told that funerals and memorial services represent only the beginning of the grieving process, not the end.

Experiencing a range of emotions

Hospices should help workers understand the range of emotions and symptoms they will experience during the grieving process: shock, denial, anger, guilt, anxiety, sleep disorders, exhaustion, overwhelming sadness, and concentration difficulties.

Most of the time a person feels several of these emotions at the same time, perhaps in different degrees. Eventually, each phase is completed and the person moves ahead. The extent, depth, and duration of the process will also depend on how close people were to the deceased, the circumstances of the death, and their own situation.

- **Take the time to grieve.** Employers need guidance in how and what to do to allow their employees to grieve. Some suggestions include:

- **Creating a memorial board.** A photo, card, or special item the person kept on her desk can be a way to remember.

- **Hold or participate in a fundraiser.** Help them honor the memory of a co-worker by helping them to raise money for the family or an appropriate cause.

- **Conduct a workplace-only event.** A luncheon or office-only memorial is a chance for co-workers to acknowledge their unique relationship with the deceased.

- **What employers can expect.** The workplace will become a place to help work through grief. Talking about the deceased helps some people

manage their grief, while others may keep to themselves. Educate employers on how to handle the varied response to the death of an employee. Guilt and anger will be evident among workers; employers should allow for these normal reactions.

Workers may also need help reacting to the deceased co-worker's replacement. They need to be made aware that anger or disappointment at the new workers' performance, personality, or work style may be more a by-product of grief than the new worker's habits or skills.

Helping children cope

Other victims of this tragedy include children. The weight of the attacks hasn't been lost on young children and teenagers. In the days following the attacks, television and newspapers recounted the events in vivid detail. Sound bites and video images all but guarantee an emotional response from children, despite their inability to completely process their feelings or to completely comprehend the disturbing events.

Hospices may have expertise in dealing with grief in instances where the death was expected and family members had some amount of time to consider the patient's death. Traumatic grief, on the other hand, is something altogether different. The same can be said about helping children deal with traumatic events.

The New York hospice association is employing the following guidelines to help children cope with the violently disruptive events:

- **Encourage parents and caregivers to take time out to talk with their children.** This is important because the child will likely hear about the events in other places, such as school.
- **Explain the tragedy in factual, but simple terms.** If they want to know more, give them the opportunity to ask questions.
- **Use the correct language.** That includes using words, such as "hijacking," "terrorism," and "dead."
- **Stress to parents that they must be honest about their own feelings.** It's acceptable for children to see sadness or grief in their own parents.
- **Parents should be given the freedom to let their children know they are scared.** But they should also help reassure their children by explaining what they are doing and what the country is doing to keep them safe. In addition, parents should ask their children what would help make them feel safe.
- **Parents and caregivers need to be told that**

they should not guarantee complete safety.

Instead, parents should focus on positive parts of family life, but also remind children that life is unpredictable at times.

- **Encourage children to continue with their daily routine.** School provides a sense of regularity and order. This will move along the process of rebuilding their sense of safety and security.

- **Get back to a normal routine.** Parents and caregivers must be encouraged to return to the activities in which they and their children participate, because routine is necessary for children to anticipate their future.

- **Allow children to struggle with their own childhood crisis, even amidst this tragedy.** Their challenges and concerns should not be minimized because of national concerns.

- **Encourage parents to hug their children and say, "I love you."** Providing reassurance and physical contact will help children relax and may placate their fears.

Time may have faded the images of Sept. 11, 2001, for some. Others may still be struggling with images of exploding airplanes and crumbling skyscrapers. And with the images likely to follow from retaliatory strikes and military casualties, hospices can expect traumatic grief and bereavement outreach to be a part of their programs in the immediate future. ■

Determine the right commercial rate

Use 20% rule to gain adequate payment

In the care you provide to Medicare patients, determining how much the federal government will pay is simple because the Centers for Medicare and Medicaid Services (CMS) determines the per diem rate on which payment is based. But where commercial payers are concerned, the process can be a lot like haggling with a used car salesman: After both sides have agreed on a payment rate, the hospice may be left wondering whether it has bought a lemon.

"The Medicare rate is as low as you should go," says managed care expert **Lisa Spoden**, president of Strategic Healthcare in Columbus, OH. "Beyond that, the rate has to be adjusted

for various factors.”

These factors can vary from one payer to the next, and each must be addressed before a hospice can determine with certainty that a proposed per diem rate is sufficient to cover the cost of caring for commercially insured patients.

According to Spoden, hospices should consider the following factors when determining a managed care or commercial rate:

- Commercial insurers usually cover a younger population with greater expectations of quality of life and care, which could result in more expensive care. In addition, pediatric patients (including hospice patients) will require more services than most adults. If too many patients require care that exceeds the payment rate, hospices might be able to make up the difference with the smaller number of younger patients.
- Managed care companies have more barriers to access, which requires another layer of hospice administration. Commercial patients require more staff time in securing preauthorization and negotiating care with the company’s case managers. Hospices do not have the autonomy or the authority they have with Medicare. Medicare does not require hospice to collect co-insurance or co-pays. Commercial insurers, on the other hand, require their patients to be responsible for a portion of the approved rate, leaving the hospice responsible for collecting payment from the patient.
- Commercial payers usually do not apply annual rate adjustments in the middle of a contract period. If a rate is insufficient, the hospice will be married to it until the contract expires.

Start from Medicare per diem rate

Contract negotiations cover a wide range of topics, from required services to office hours, all of which can affect the payment rate. But with the plethora of items that must be covered, it would be easy to slack off on the details surrounding commercial rate determination.

So how do you determine whether a commercial rate is fair after considering the above factors? According to Spoden, the starting point should be your current Medicare per diem rate. The reason for this is that any contracted package of services described as hospice must contain the services that are required by Medicare’s conditions of participation (COPs). Outside of commercial rate negotiations, general contractual

negotiations should strive to keep COPs intact when deciding which services would be provided to commercially insured patients.

What hospices fail to recognize is that the way managed care organizations (MCOs) operate can directly contradict federal and state regulations that govern hospices. For example, MCOs normally insist that their own case manager manage the patient, but Medicare’s COPs require hospices to retain medical management of a patient during a hospice stay.

The first business of managed care contracting is to make sure a number of non-negotiable items are included. If the MCO balks at including language stipulating that the hospice maintains medical management of the patient, for example, negotiations should be ended.

Medicare standards for non-Medicare patients

In addition, Spoden recommends that hospices use the following points to ensure that the MCO understand the importance of maintaining the Medicare standard for non-Medicare patients:

- COPs require that hospices have responsibility to professionally manage the care and services of their patients for palliation and management of the terminal disease. Limiting care to a commercial plan enrollee could be construed as a violation of federal conditions of participation and result in the hospice’s loss of Medicare certification.
- Federal law requires hospices to make available the full continuum of prescribed services, and hospices are required to deliver the same level of services to all patients regardless of payment source.
- A nursing visit alone cannot be labeled as hospice care. An insurer cannot label a benefit as a hospice visit unless it meets the criteria defined by law.
- State and federal regulations require that the plan of care, interdisciplinary care team, case management, and use of ancillary services be under the direction of hospices.
- Hospice and home care services are separate licensed entities, and their services, functions, and contract language must be kept separate.

When commercial payers are convinced that contracted hospice services should reflect Medicare COPs, hospices can begin negotiating a fair commercial per diem rate. While there is no set “fair rate” or a handy pricing guide to use like a shopping list, Spoden says there is one

Define your terms in an MCO contract

Here are some useful definitions

Ensuring clarity in a contract with a managed care company requires that both entities be speaking the same language. Here are some definitions it would be useful to have in your contract:

- **Hospice:** An organized program that provides palliative care to terminally patients and supportive service to patients, their families, and significant others in both home and facility-based settings. A 24-hour on-call service is available to evaluate the patient's changing needs. The range and intensity of services will be consistent with those in the patient's plan of care and approved by the health plan. Hospice services to be provided by the hospice will be in accordance with the patient's individualized plan of care and include all the equipment, medication, treatment, and care required to manage the terminal illness of each health plan patient admitted to the hospice provider.

- **Physician services:** Physician services provided by the hospice will be limited to those associated with assisting in the coordination of the hospice program and those associated with the quality assurance and utilization review functions for the hospice program. Direct physician medical care is billed separately from the hospice per diem.

- **Unrelated services, equipment, medication, treatment, and supplies:** Items not related to the terminal condition and in the patient's plan of care are not covered under the hospice

benefit but may be covered under other benefit categories as stipulated by the plan.

- **Palliative vs. curative:** It is understood that hospice care is palliative rather than curative in treatment goals and treatment methods and that the definition of accepted palliative goals and methods is exclusively the province of hospice for all patients.

- **Patient residence:** A patient's residence is a private home, nursing facility, intermediate care facility, group home, assisted living facility, licensed hospice facility, or other alternative residence.

- **Routine hospice care:** Intermittent scheduled care provided to hospice patients in their place of residence. A 24-hour on-call service is provided. As detailed in the patient's care plan, services may include:

- physician-directed interdisciplinary case management focused on patient symptom control;

- services by licensed nurses, social workers, chaplains, counselors, nursing assistants, and volunteers;

- family counseling services to family members during the time the patient is receiving hospice care;

- bereavement care and counseling for family members for at least one year following the patient's death;

- all interventions related to the terminal condition and necessary for the implementation of the patient's plan of care, such as therapies, medications, and routine medical supplies.

The above definitions represent only a portion of the language that needs to be included in a managed care contract to make it hospice-specific. Other attachments address eligibility, fee schedules, and billing procedures. ■

rule of thumb that may help hospices determine a fair rate — the 20% rule.

In the past, commercial payers traditionally paid 80% of the Medicare rate, leaving providers with the options of either swallowing the difference or getting patients to make up the difference.

Hospices are already aware that Medicare's per diem rate is outdated and does not allow for rising costs in hospice care. The difference is often subsidized by donations. But while hospice boards feel it is justified to subsidize government-sponsored programs that fund health care for the

elderly, poor, and disabled, they are likely to be less inclined to subsidize a profit-making organization such as an MCO.

So rather than take a 20% cut from the Medicare rate, Spoden says, hospices should strive for a rate 20% above the Medicare rate — a tall order for organizations that aren't very experienced in negotiating contracts with companies that are quite experienced in getting contracts that favor their interests.

But it can be done, says Spoden. Hospices must prove to MCOs that the proposed rate is justified

by making the case that the Medicare rate is inadequate and that more money is needed to care for the insurer's patient population adequately.

You can also use cost reports, those dreaded documents that hospices have been required to submit to the CMS, to help you out. Some hospices now have two years' worth of cost reports, which can show an organization's rising costs, particularly in the areas of drugs and nursing.

If a hospice is not prepared to use its cost report data, then it may help to explain changes in the industry that have directly affected a hospice's costs. Last year, Milliman USA, a Chicago-based actuarial and consulting firm, released a landmark study that showed Medicare rates were based on outdated cost data.

Gap between cost and payment poses threat

According to the study of 10,000 patients cared for in large hospice settings, the current reimbursement rate for routine home care, which accounts for 95% of hospice days used by Medicare patients, does not cover the costs incurred by hospices. It says the gap between what hospices are paid and how much it costs to deliver care poses a real threat to hospice programs nationwide.

Specifically, hospices can cite the following information from Milliman USA's report:

- Increasing cost of prescription drugs. New technology, including breakthrough therapies and prescription drugs, has increased hospice costs well beyond Medicare's market basket update, which accounts for cost increases and adjusts reimbursement rates for all Medicare providers.

In 1982, when the hospice benefit was established, prescription drug costs amounted to about \$1 of the \$41.46 per diem payment. Prescription drug costs have soared since then, totaling \$16 per day of a \$98.96 per diem payment.

Prescription costs across the health care landscape are a hot topic among lawmakers, many of whom want to see beneficiaries get a break from rising drug costs. Depending on the source of information, drug costs are increasing 15% to 20% per year, experts say. Hospice drug costs are rising 18.3% per year, according to Hospice Pharmacia, a Philadelphia-based consulting firm. Because drug costs make up a significant portion of a hospice's direct costs, the firm predicts those expenses will likely double in three to five years if left unattended.

Experts blame a combination of factors for the

rising cost of drugs: higher drug utilization, inappropriate drug utilization, and an increasingly aging population.

- **Declining length of service.** When Medicare first set the hospice payment rate, the government based it on a length of service that was twice as long as the current length of service most hospices are experiencing.

"Average length of service has dropped to 40 days, while the original Medicare Hospice Benefit set the rate based on a 70-day length of service," the report stated.

Hospices have suffered from short length-of-stay allowances and have struggled to come up with ways to bring patients into hospice more quickly. Most hospice leaders blame current eligibility requirements that force physicians to make the uncertain prediction that a patient will die within six months as a result of their illness. In addition, reimbursement rules also mean physicians lose revenue as a result of a hospice referral.

First and last days cost the most

Declining length of service exacerbates the already low reimbursement rate, widening the gap between cost and reimbursement. That's because hospices encounter higher costs in the first few days following admission and in a patient's final days. Medicare per diem payments are often not enough to cover the cost of program introduction at admission and intensive care at the end of a patient's life.

- **Outpatient hospital therapies.** The advent of more innovative and expensive palliative care methods has contributed largely to the increase in hospice costs. Among those are palliative chemotherapy and radiation treatments. According to Milliman USA's report, the cost of these types of therapies has grown to more than \$17 per day, while Medicare originally allocated about \$3.

The Milliman USA report represents the first of a series of hospice reports. With hospices filing cost reports this year, CMS will have its own cost data on hospices to help determine future reimbursement.

The end result, Spoden says, is a rate that will likely fall somewhere between Medicare's current hospice rate and 20% above it.

The prevailing message is that hospices shouldn't go into contract negotiations blindly.

"You have to go in armed with evidence and ready to stand up for yourself," says Spoden. ■

Contracts should include non-negotiable points

Here's a sample list to include in your next contract

Settling on a per diem rate with commercial payers is only part of the process of negotiating a contract with a managed care organization (MCO). Other parts of the process will determine whether a hospice and MCO will operate as partners or whether the hospice will be obligated to indentured servitude for the life of the contract.

MCOs often are reluctant to reword their original documents, preferring instead to use addendums to contracts to cover hospice-specific language and definitions, says managed care expert **Lisa Spoden**, president of Strategic Healthcare, a Columbus, OH-based consulting firm.

First and foremost, contracts should be amended to include the basic conditions of participation required by Medicare. Anything less — even where commercially insured patients are concerned — can result in your hospice losing its Medicare certification.

If the MCO is willing to abide by hospice regulations and include hospice definitions in the contract, the next step is to introduce an addendum to the contract. Spoden offers the following attachments to clearly spell out what is expected from both parties. **(For information on suggested definitions, see story, p. 125.)**

Spell out eligibility

Once the MCO understands what hospice care is about and how it is delivered, the next step is to make sure you and the MCO understand the details regarding how a patient is referred to hospice care and how you get paid.

The second attachment deals specifically with hospice service eligibility. According to Spoden, the attachment should include the following four points:

- 1.** A patient must be diagnosed as having a terminal condition by a licensed physician and have a limited prognosis, if the disease takes its normal course.
- 2.** The patient and physician must consent to hospice care.
- 3.** The patient must reside in the service area covered by the hospice.

4. There are no restrictions as to age, gender, race, color, residence, marital status, citizenship, ethnic origin and membership, physical or mental disability, religious belief, sexual orientation, or disease.

Again, the attachment should stress that hospice care is palliative rather than curative and that the care and methods used in palliative care are the exclusive domain of the hospice.

The language should also stipulate that the responsibility and liability of hospice in the provision of services to health plan members should be limited to the care spelled out in the patient's plan of care and that the management of patient care is the responsibility of hospice.

The attachment should also clearly state that the final determination of whether a patient meets admission criteria rests in the hospice's hands.

Pay attention to billing details

Once eligibility language has been agreed to, the next topic is billing and reimbursement. Negotiating a fair per diem rate is a major part of contract talks. The ideal reimbursement rate can vary from one agreement to the next, depending on the types of services a hospice will be required to provide. In any case, it should not be a rate below what Medicare pays because that will place a greater burden on community donations to cover costs.

But the nuts-and-bolts details surrounding billing and payment require close attention, as well. Spoden says an attachment to the contract should spell out what the all-inclusive per diem rate includes and when payment is expected.

An example of attached contract language is: "The health plan agrees to pay within 30 days from receipt of a clean copy bill for covered hospice services provided to health plan members. In the event that the payment is not made within 30 days, interest will accrue on the amount owed to the hospice at a rate of 5% per day."

The term "clean copy bill" can cause some trouble, Spoden says. Because an MCO can find the simplest fault in a claim and return it without payment, the MCO can get around the 30-day requirement. To avoid disagreements, Spoden advises that the MCO provide a clean bill as an example and that the sample bill be attached to the contract.

The contract also should:

- Specify the billing form to be used. It would

be preferable to use UB-92, which is similar to the HCFA 1500 claim form, because hospices would be more familiar with it.

- Require the MCO to provide any additional information needed to bill the health plan or any other third-party payer for services delivered by the hospice.
- Specify that the patient's date of death is considered a day of care and that the health plan will pay the per diem for that day's care.

As you can see, the soundness of a managed care contract depends on whether the hospice pays attention to the details. The more details the hospice is able to insert into the contract, the more it will read like a contract written for a hospice, rather than a contract written for nursing homes and home health agencies. ■

Get aggressive with public awareness

Step up PR efforts

In the game of public awareness, if the public doesn't know who you are or what you're selling, chances of profitability — not to mention survival — are slim. While much of the hospice industry's efforts have focused on educating referral sources on the benefits of hospice care and the need for timely referrals, the effort to affect consumer behavior has not received the same level of attention.

Consider this: More than 90% of Americans do not know that hospice care is a fully covered Medicare benefit for patients at the end of life and includes all that Americans say they want for their loved ones, including pain management and emotional support.

Pharmaceutical companies have provided the best example of how an industry can captivate consumers and prompt them to pressure physicians into prescribing drugs that may alleviate symptoms or cure their diseases. Is it possible for hospices to take a page from pharmacy companies' playbooks to garner the kind of enthusiastic interest that could lead to a greater number of hospice referrals?

The answer, according to experts in hospice public relations, is yes and no. Yes, hospices can learn from the consumer-focused approach of drug

companies. However, the mass media that inundates television viewers, magazine readers, and radio listeners with promises and images of people unencumbered by disease or debilitating symptoms comes with too expensive a price tag.

In addition, drug companies are able to keep consumers' attention because most people are comfortable with the notion of using drugs to improve their quality of life. On the other hand, most people are not comfortable with the topic of dying, which could result in a mass media campaign falling on deaf ears and a boondoggle of magnificent proportions.

"It will take a grass-roots effort," says **John Millett**, a spokesman for the National Hospice and Palliative Care Organization in Alexandria, VA.

Millett says raising public awareness of hospice must begin by pecking away at society's inability to discuss death. Consumers must be educated via more intimate methods, such as meetings with community groups. Large-scale public awareness should be accomplished through coordinated media campaigns like those done in conjunction with the Bill Moyers public television series *On Our Own Terms* on death and dying.

Community responsibility

While there are national efforts under way to increase public awareness, hospices must take up the cause of raising awareness in their own communities. The challenges are the same locally as they are nationally. Here are some facts about American's attitudes toward death and dying:

- More than one out of every four adults is not likely to discuss with a parent issues related to the other parent's death, even if the parent was terminally ill and had less than six months to live. Americans are more likely to talk to their children about such sensitive topics as drugs and safe sex.
- Fewer than 25% of people have thought about how they'd like to be cared for at the end of life and have put it in writing. While 36% say they have told someone about how they would like to be cared for, focus groups show that people often view a passing comment about how they would like to die as informing their loved ones of their wishes.
- Even though people are not talking about how they want to be cared for during the last stage of life, half of Americans state that they will

rely on family and friends to make decisions about care at the end of life.

- At the same time, people say that making sure that the patient's own wishes are enforced at the end of life is the most important service available for a loved one who is sick with less than six months to live.

- About one-third of people are unsure whom to contact to get the best care during life's last stages; 30% said they would contact their doctor, and 13% mentioned hospice.

"We don't recognize that they are our public awareness problems, too," says **Don Pendley**, president of the New Jersey Hospice and Palliative Care Organization in Scotch Plains. For most hospices, public awareness is so weak that most start from the premise that there is a lack of information. To increase public awareness, hospices must promote a strong message that is consistent with other messages being promoted by other hospices or by industry leaders, and the campaign must be ongoing, rather than sporadic.

"If the community doesn't know you, they aren't going seek out hospice care," says **D. Rigney Cunningham**, executive director of the Hospice and Palliative Care Federation of Massachusetts in Norwood.

In 1998, the Hospice and Palliative Care Federation embarked on a public awareness campaign, called Choosing Hospice, funded by a grant from the Robert Wood Johnson Foundation. The project built upon a 1996 *Boston Globe* supplement on hospice care and the growing discussion about end-of-life care. (See related story, *Hospice Management Advisor*, July 2001, p. 78.)

The project reprinted 107,000 copies of the *Boston Globe* supplement, developed public service announcements about hospice, published and distributed a hospice consumer guide, assembled a photography exhibit, and produced a 10-minute documentary on hospice that can be used in conjunction with a speakers' bureau.

In short, Cunningham says, the federation set out to raise public awareness of hospice by implementing a multimedia approach. The hope was to create a model campaign that would raise awareness throughout the state with components that local hospices could employ to raise awareness in their own communities.

Similar to the Massachusetts effort, Pendley says the hospice message should focus on how hospice care improves the quality of a patient's life and how it helps families cope before and after the death of a loved one.

He is skeptical that a blitz of hospice advertising would be cost-effective. But hospices should not be wary of delivering the message to a wider audience. Although most people do not currently need hospice care, the hope is that people will recall the message when the appropriate time comes.

In the end, consumers will determine the success or failure of hospice, both Cunningham and Pendley say. If hospices can affect consumer habits, the care can be elevated in the same manner as maternity services were improved a generation ago by consumer demands. ■

Federal study focuses on pediatric palliative care

Children don't receive same level of care as adults

Seriously ill children frequently don't get appropriate pain management and supportive services at the end of life because their conditions and treatments don't fit existing care models designed for adults. But federally funded demonstration projects in five states are designing new ways of providing services to kids — ways that don't require parents and physicians to abandon treatments aimed at a cure in order to examine other options.

"The bottom line is, from the patient and family standpoint, we want to allow them to choose hospice-type care, which is really comprehensive, compassionate care that is known as hospice, from the time of the diagnosis of a life-threatening condition — even when there is hope for a cure — through bereavement follow-up if a cure is not obtained," says **Anne Armstrong-Dailey**. She is the director of the Alexandria, VA-based Children's Hospice International (CHI), the organization in charge of administering the projects and distributing the funds.

Last year, CHI received congressional funding for the first five demonstration projects of its Program for All-inclusive Care for Children (PACC). The PACC programs develop and coordinate comprehensive systems of care that allow seriously ill children and their families to have access to palliative pain management, supportive counseling, and, in some cases, home health and hospice services, even while curative treatment is

pursued, says Armstrong-Dailey. This year, the program received an additional \$885,000 from Congress, which will allow CHI to continue funding the existing five projects and start a sixth demonstration project in another state.

Studies have shown that more integrated models of providing palliative care and hospice support work best for children, as opposed to traditional “adult” models that have focused on providing palliative treatments to patients when there is little or no hope of recovery.¹⁻³

Children have unpredictable trajectories

Although advocates urge providers to see palliative care as part of the overall care plan for all patients, including adults, this inclusive approach is especially important for children, says **Cynda Rushton**, DNSc, RN, FAAN, clinical nurse specialist in ethics at Johns Hopkins Children’s Center in Baltimore. “Part of the problem with children is that sometimes their disease trajectories have been unpredictable,” she explains. “Children who we think are not going to survive — they do. Then, you are sort of on this roller coaster of trying to figure out what the outcome will be.”

In 1982, changes in the Medicare and Medicaid hospice eligibility standards required patients to have a physician’s diagnosis that they were in their last six months of life. Additionally, all curative treatments must have stopped in order for hospice services to be reimbursed through Medicare and Medicaid. Many private health plans followed suit. The result is that children are referred to hospice very late in their course of illness, if at all, says Armstrong-Dailey.

“Seldom is a physician able to say — until it’s at the very last moment — that the child is at death’s door,” she explains. “Most often, pediatric patients are in and out of the terminal stage for a number of years. And, how many parents do you know, or how many pediatricians do you know, who would be willing to stop curative treatments on a child, even if his or her chance for survival were one in 10 million?”

Even if hospice referrals could be made in a

timely manner, however, many communities don’t have the resources to provide appropriate end-of-life care to children outside the acute-care setting, says Rushton. “We don’t have a lot of providers skilled enough to provide the care,” she continues. “Some of it is lack of education, and some of it is lack of specialized resources. Children, even in the end stages of their lives, still are usually receiving quite a bit of [medical] technology. We need people to be able to provide the emotional, psychosocial, and spiritual support, as well as some of that high-tech nursing care, in the home.”

‘The time of crisis is the time of diagnosis’

Because seriously ill children typically need a high level of medical interventions for a longer period of time, it is very difficult to get them plugged into existing services, she says. One of the main goals of PACC is to secure hospice benefits for chronically ill children who may not necessarily be near the end of life, says Armstrong-Dailey. Families dealing with the serious, life-threatening illness of a child desperately need the supportive counseling and health care services that hospice provides for dying patients and that a comprehensive program should provide for all patients, she says. “I have personally talked with tens of thousands of parents over the past 20 years, and without exception, the parents will tell me that the time of crisis is the time of diagnosis, even when there is still hope for a cure,” she says. “Most parents will tell you that the time of the child’s death is anticlimactic by comparison.”

Parents of seriously ill children feel tremendous pain and guilt at the time of diagnosis, particularly if the disease is genetically linked, she notes. Families need help dealing with these issues early on in order to preserve the strength of the family unit and make appropriate decisions about the care of the child. “By dealing with these emotions, we can help families look at the situation in a realistic way and realistically examine what the options might be,” says Armstrong-Dailey. “It can help prevent the dysfunctional, destructive behavior that

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can shatter families. Without support, you often see an enormous increase in alcohol and drug abuse within families and destructive behavior by surviving siblings.”

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News From the End of Life

Alzheimer's drug may be more beneficial

The benefits of donepezil hydrochloride, marketed as Aricept, may extend into more advanced stages of Alzheimer's disease than previously investigated, according to a study of patients with moderate to severe Alzheimer's disease.

The study, published in the Aug. 28 issue of *Neurology*, found that Aricept, which is approved for the treatment of symptoms of mild to moderate Alzheimer's disease, conferred significant benefits vs. placebo in patient function, cognition, behavior, and activities of daily living, with very good tolerability. In addition, improvement in all behavioral symptom items on the neuropsychiatric inventory favored Aricept.

The Moderate to Severe Alzheimer's Disease Study is the third Aricept study to be published in *Neurology* recently. Two additional placebo-controlled studies of patients with mild to moderate Alzheimer's disease were published in the Aug. 14 issue. A function study found that one year of treatment reduced the risk of functional decline. The other previous study demonstrated that the drug maintained cognition, activities of daily living, and global function for one year.

“These three research articles in *Neurology* represent an important convergence of information,” says **Howard Feldman**, MD, at the University of

British Columbia Hospital's Clinic for Alzheimer's Disease and Related Disorders in Vancouver, BC, Canada. “Alzheimer's research holds promise for the future, but doctors who care for mild to moderate Alzheimer's patients and their caregivers should understand the benefits Aricept treatment offers today and may continue to offer. The findings . . . further reinforce the significance of Aricept as an important choice to preserve patients' independence longer while they live with the disease.”

Other study highlights include:

- Aricept-treated patients remained stable throughout the study on measures of function, while placebo-treated patients showed functional decline.
- The Aricept-treated group showed less decline on average compared with placebo-treated patients on both instrumental and basic activities of daily living.
- The Aricept-treated group showed statistically significant overall improvement vs. placebo

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Editorial Questions

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in behavioral disturbances associated with Alzheimer's; a subanalysis of behavioral domains showed statistically significant benefits in apathy, depression, and anxiety. ▼

MDs should focus on dying children's quality of life

A study published in September found that terminally ill infants whose families were given special counseling were more likely to die in a peaceful setting and were subjected to fewer invasive procedures than infants with similar terminal conditions during their last 48 hours of life.

The study, published in the September issue of the journal *Pediatrics*, is one of the first to look closely at a palliative-care approach for dying newborns and premature infants.

"We don't always have to aggressively treat something," said **Steven Leuthner**, MD, of the Medical College of Wisconsin in Milwaukee, the lead author of the study. "We are not talking about doing nothing. We are providing some comfort, and therapies to allow you to achieve whatever goals you have set for yourself and your child for whatever limited amount of time there is left."

The study prompted a joint statement from the American Academy of Pediatrics (AAP) and the American Pain Society (APS). The organizations called for a national effort to improve the control of acute pain in infants, children, and adolescents. According to the statement, there are many barriers to treating acute pain in children, including:

- the myth that children, especially infants, don't feel pain the way adults do;
- a lack of assessment and reassessment for pain;
- fears about side effects of pain medications, including respiratory problems and addiction;
- the belief by some health care workers that pain builds character in children.

"The AAP and APS feel that most acute pain experienced in medical settings can be prevented or substantially relieved," the joint statement says. "To accomplish this, physicians need to expand their knowledge about pediatric pain management principles, provide a calm environment for painful procedures, use appropriate assessment tools and techniques, anticipate painful experiences, and involve families in creating solutions for their child's pain." ▼

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Home health PPS software is available

Home care agencies may now visit the Centers for Medicare and Medicaid Services (CMS) web site to download the PC version of the Medicare PPS Pricer software that is used to calculate home health prospective payment system (PPS) payments on all home health claims.

The PPS Pricer makes all reimbursement calculations applicable under PPS, including percentage payments on requests for anticipated payments, claim payments for full episodes of care, and all payment adjustments, including low utilization payment adjustments, partial episode payment adjustments, significant change in condition adjustments, and outlier payments.

The software allows agencies to predict and validate payment amounts for their claims, using the same software used by regional home health intermediaries' systems. To download, users must have an IBM PC or clone with a hard disk drive for Microsoft Windows 95 or newer with at least 8MB RAM. The software is available at: www.hcfa.gov/medicare/nm75ght/priceint.htm. ■