

# HOSPICE Management ADVISOR

Integration • Outcomes • Managed Care • Medicare Compliance • Risk Management • QI • End-of-Life Care

## INSIDE

■ **Volunteer screening:** Criminal background checks may be a necessity when considering prospective volunteers. . . . . 100

■ **Patient education:** Hospitals are stepping up their discussion of end-of-life care options, including the use of advance directives . . . . . 102

■ **Pediatrics:** A federal panel looks for ways to pay for end-of-life care for children . . . 104

■ **E-philanthropy:** Fundraising expert says the Internet can help hospices in their fundraising efforts . . . . . 105

■ **News from the End of Life:** VA picks care sites for end-of-life project. . . . . 106

SEPTEMBER  
2001

VOL. 6, NO. 9  
(pages 97-108)

## Bereavement outcomes measurement still a distant goal

*Common sense still the best tool for program improvement*

In many ways, caring for those left behind following the death of a loved one can be more difficult than caring for the hospice patient. The majority of care for a 50-year-old man dying of cancer, for example, may be focused mostly on pain management while he spends the remainder of his life surrounded by family and friends.

But there are no shots or pills that relieve the pain caused by grief. And unlike physical pain, there is no immediate indication that the balm administered by professionals is working.

To that end, the hospice industry has been trying to apply outcomes measurement to bereavement care, in much the same way that the rest of the industry has applied the discipline to clinical procedures. But moving from having no measurable data to compiling usable information that will allow hospices to compare their own bereavement programs to nationally compiled data has been tantamount to sending a man to the moon.

### *How do you know you're being effective?*

At the heart of the industry's quest for bereavement outcomes is the need for hospices to determine whether their efforts are meeting the goals they set for their program and for the individual clients they serve.

In short, hospices are asking: How do we know if our program is as effective as it can be?

"That's a question we've been asking ourselves," says **Noreen Carrington**, LMSP, director of bereavement and volunteer services for San Diego Hospice, whose bereavement program is one of the largest in the country.

If one of the country's standout programs acknowledges that it, too,

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is unable to collect measurable data to evaluate the effectiveness of its programs, then it stands to reason that most other hospices — large and small — have yet to take their first steps.

Most hospice programs approach bereavement care by applying a set of goals laid out in a bereavement care plan. These goals may call for bereavement professionals to help grieving clients:

- to express all the feelings over this loss: anguish, longing, relief, anger, depression, numbness, despair, aching, guilt, confusion, and often unbearable pain;
- to let the nonnegotiable and excruciating reality sink in that they will never again be in the physical presence of their deceased loved one;
- to review their relationship with the deceased patient from the beginning and to see the positive and negative aspects of the person and the relationship;
- to identify and heal unresolved issues and regrets;
- to explore the changes in their family and other relationships;
- to integrate all the changes into a new sense of themselves and to take on healthy new ways of being in the world without this person;
- to form a healthy new inner relationship with this person and to find new ways of relating to him or her.

San Diego Hospice is like many hospices around the country in that it employs standard bereavement programs that are a combination of therapy and support, such as counseling, support groups, and a variety of community resources.

### ***Database would allow national comparison***

The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, has also recognized the importance of developing outcomes-based bereavement programs. It has taken the first steps toward developing a national database of bereavement information so that its members can one day compare the results of their bereavement programs to those of others and make necessary changes to improve their own outcomes.

In conjunction with the National Hospice Work Group, the NHPCO examined the perceived effectiveness of support given by hospice staff. Researchers conducted surveys two months following the death of patients and after 13 months. Overwhelmingly, the survey found

family members received pre-death support, enabling them to prepare for their loved ones' deaths. Of the 1,739 surveys, 1,612 (93%) of the respondents indicated effective pre-death emotional support, while 127 (7%) indicated lack of emotional support.

Thirty percent of these surveys were sent to caregivers with hospice care for seven or fewer days, 32% were sent to caregivers with hospice care for eight to 30 days, and 38% were sent to caregivers with hospice care for 31 or more days. Pre-death emotional support was indicated by 91.1% of those who received care for seven or fewer days, 92.3% of those who received care for eight to 30 days, and 94.3% of those who received care for 31 or more days.

### ***Completing the data picture***

Clearly, this is one slice of a very complicated phenomenon. "We want to collect more data to paint a complete picture," says **Stephen Conner**, PhD, vice president of research for the NHPCO.

The outcomes project did not attempt to measure risk factors that may prolong grief. Indications of complicated grief or the possibility that a family member will experience chronic grief include:

- **Guilt.** The survivor feels guilty for a number of reasons, including trying to move on or for having failed as a caregiver.

- **Unrelenting anger and hostility.** The survivor cannot engage normal daily activities without feelings of anger.

- **Increased drug and alcohol use.** Drugs and alcohol become a means of numbing pain or escaping reality.

- **An inability to carry out daily tasks or responsibilities months after the loss.** For example, the survivor fails to keep up with housework or cannot complete required duties of his or her job.

- **Thoughts of suicide.** The survivor not only expresses a desire to die, but describes how he or she would follow through.

- **Unrelenting loneliness.** Despite the support of family, friends and counselors, the bereaved feels isolated and alone.

Experts believe the measurement of these characteristics of grief will hold the key. But the NHPCO is not the first to study bereavement outcomes. Prior researchers have experienced limited success in trying to discover the important factors that result in positive bereavement

# Steps to take to monitor bereavement

Hospices can monitor their bereavement programs by taking the following steps, says **Cendra Lynne**, PhD, director of Grief.Net, an on-line resource for bereavement researchers and for those looking for bereavement support:

- **Understand the population you serve.**

Based on ethnic and cultural characteristics, hospices must tweak their approaches based on beliefs and customs held by those the hospice serves.

- **Survey survivors to get their feedback.**

Hospices should create a survey that measures survivor satisfaction with a number of key elements, such as support, access to counseling, and whether programs were effective. Lynne

notes that responses to this survey will be more subjective than objective and thus not very scientific. Hospices may experience high satisfaction in nine out of 10 responses because support in such a difficult time will likely be perceived as positive. But the survey's value is that it provides direct feedback from clients. "You're not looking for objectivity," Lynne says. "You can't define what is helpful by someone else's standards. It has to be defined by the individual."

- **Keep in touch with survivors.** Traditionally, surveys do not garner a high response rate. This means it's important to go back to survivors and asking them what could have been done better.

- **Trust the instincts of your most experienced staff.** "They already know a great deal," Lynne says. "They know if you are helping." ■

outcomes, including how age and culture affect the grieving process.

Past research focused on the following indicators to measure grief both at the time of the loved one's death and a year later:

- change in percentage of times the participant found memories comforting;
- change in percentage of time the participant found that grief influences their ability to make day-to-day decisions;
- change in participant rating of the intensity level of their sadness.

While hospices are not much closer to practical bereavement outcomes programs, research has yielded valuable insights. For example, while hospice programs generally provide bereavement care for a year, research has shown that many people continue to grieve well beyond the first year, perhaps even more than when the loved one first died. Experts now believe that the prolonged grief is not necessarily an indication of ineffective grieving, but is a function of an individual need to grieve longer. It is that very aspect of grief that makes bereavement outcomes measurement so difficult.

"If we knew how to do it, we'd already be doing it," says **Cendra Lynne**, PhD, director of Grief.Net, an on-line resource for bereavement researchers and for those looking for bereavement support. "The problem is that there is a wide variety in the normalcy of grief, and we don't understand how grief works."

So, absent of any working outcomes measurement tool, what can hospices do to ensure the continual improvement of their programs? The answer, Lynne and Carrington say, lies within the individual hospices themselves and the expertise they already have.

"Someone who has worked for 15 years with grieving families is the best resource a hospice can have," says Lynne.

Bereavement programs can be improved through common sense, Lynne adds. Hospices that understand the population they serve and then tailor care to the individual will have gone a long way to establishing a foundation for improvement.

At San Diego Hospice, a bereavement plan of care is initiated when the patient is admitted to hospice following a terminal diagnosis. This is not unusual among hospices, but it underscores the simplicity of program improvement.

Based upon the initial assessment of the caregiver, individual goals, such as acknowledgement of feelings and of loss, are set throughout the patient's hospice stay and for the months or years following death. While a hospice may not be quantifying its ability to meet its goals throughout the plan of care, workers should be in tune with goals that are typically difficult to achieve or take longer to achieve than others.

"At a given place in time, a patient should be able to move on with their lives," says Carrington. ■

# Don't ignore volunteer screening process

*Criminal background alone is insufficient*

Hospices place a great deal of responsibility on their volunteers. Those whose charity is their time and compassion often provide in-home care to patients and family with little or no supervision. But do hospices really know enough about their volunteers to entrust them with such important tasks?

Probably not. With competition for volunteers so fierce and the work so challenging, many hospices find it difficult to turn volunteers away, instead opting to find jobs suitable to their talents.

That's fine, says **John Patterson**, senior program director for the Non-Profit Risk Management Center, a Washington, DC-based organization that provides assistance and resources on a variety of risk management, liability, and insurance issues. If, however, a volunteer is being asked to go into the patient's home unsupervised, a thorough screening of the prospective volunteer must be done, he says.

The safety of patients and their families is at stake. It would be easy for a predator to take advantage of the trusting relationships that hospice workers and volunteers develop with the patient and family. Failing to screen new volunteers adequately also leaves a hospice vulnerable to a lawsuit if a volunteer harms a client.

The basic legal standard that applies to employee screening is reasonableness under the circumstances, says Patterson. If a hospice's screening process is challenged in court, a judge or jury will evaluate the reasonableness of the process the organization used to disqualify unfit people from serving its patients.

A court also will consider whether the organization knew or should have known of the risk of harm and whether the screening process, or lack of it, caused or contributed to the harm. In short, failing to conduct any screening may be considered unreasonable, which can lay the groundwork for an unfavorable judgment.

"Every nonprofit organization is responsible for taking reasonable measures to protect service recipients from harm," says Patterson. "This responsibility extends to all facets of a nonprofit's interactions with its clientele.

"While not a panacea, careful screening of the paid and volunteer staff who work with vulnerable populations is an important risk management strategy. The failure to adequately screen applicants may place service recipients in dangerous situations. Checking the criminal history records of applicants is one valuable tool in a comprehensive screening process," he explains.

Volunteer screening includes interviewing the potential volunteer, checking his or her background, and training. Depending on the job a volunteer is being asked to perform, hospices may wish to make the screening process less intensive for those who would be doing in-office administrative work and more thorough for those who would have direct contact with clients.

The first part of the screening process is the application, which is followed by an interview. A volunteer's entrance into the hospice work force should be largely similar to that of a paid hospice worker. Volunteers should be required to complete an application that asks for references and if the prospective volunteer has ever been convicted of a criminal offense.

Further, hospice administrators must make a priority of checking the references and verifying the information on the application, rather than just confirming references from time to time. By making this a hospice policy, those in charge of recruiting volunteers would be encouraged to follow the practice consistently.

While the application allows volunteers to self-disclose past offenses, it is not unreasonable to assume that prospective volunteers might withhold information, which makes it necessary to consider doing criminal history checks.

But before incorporating criminal history checks into the screening process, a hospice must establish clear guidelines stating which offenses are relevant, which ones will disqualify an applicant, what other factors will be considered, and how the rights of the applicant will be preserved. These screening criteria should be applied both to offenses disclosed in the application and those revealed through criminal background checks.

Patterson warns hospices not to rely too much on criminal background checks, but instead to focus on the larger picture painted by the entire screening process. At the same time, hospices must be aware of the risk of not doing these checks.

"Think of yourself sitting on the witness stand trying to explain why you didn't do a criminal background check," he says.

Because criminal background checks in most states are not free, hospices might want to limit the use of criminal history record checks to positions that call for direct contact with children and elderly people.

When establishing screening criteria, organizations must take into account state and local laws and regulations. Some states have screening or licensing requirements for people who have substantial contact with children or other vulnerable individuals, such as elderly and disabled people. State-specific requirements might include specific offenses that automatically disqualify applicants for some assignments. Absent of specific requirements, however, crimes against persons, such as sex-related crimes, battery, burglary, and robbery — felony or misdemeanor — should be cause for disqualification, Patterson says.

If a hospice serves children or places volunteers in homes where children are present, potential volunteers should be permanently disqualified if their criminal records include any of the following:

- past history of sexual abuse of children;
- conviction for any crime in which children were involved;
- history of any violence or sexually exploitive behavior.

Besides offenses cited in state-specific regulations, other offense should be included in the screening criteria be based on the relevance the offense has to the volunteer position, Patterson says. For example, a volunteer with a history of drug-related offenses may feel tempted to steal prescription drugs from the home of a patient.

The more specific the criterion, the more useful it is for screening, Patterson says. Specific offenses pinpoint the areas of concern and do not unnecessarily disqualify applicants. Some organizations include broad categories of offenses in their lists of disqualifying offenses, such as drug-related offenses. This category encompasses everything from a single misdemeanor possession of less than an ounce of marijuana to felony drug racketeering. Hospices should consider narrowing their categories to target specific relevant offenses committed within a defined time period.

There are other factors to consider, as well. Patterson points to the following factors that he says should be considered together, rather than individually:

- **The age of an individual at the time of the offense.** In some states, juvenile records will not be available because they are protected by

confidentiality laws.

- Societal conditions that may have contributed to the nature of the conduct. While societal conditions should not serve to excuse illegal behavior, the context in which the illegal behavior occurred might be considered.

- The probability that an individual will continue the type of behavior in question. Criminal history records that document a continuing pattern of repeated criminal offenses provide justification to believe that the individual represents a high risk for future criminal conduct.

- The individual's commitment to rehabilitation and to changing the behavior in question. When an applicant has a criminal history record that includes potentially disqualifying offenses, the organization may consider the steps the applicant has taken toward rehabilitation. ■

## Training program tells if volunteers are able

### *Avoiding the appearance of impropriety*

When developing a volunteer screening program, the last piece of the process is the training program, which should be used not only to educate volunteers but also to gauge their ability to fulfill the tasks they will be asked to perform.

The training program serves to help volunteers avoid the appearance of impropriety. For example, volunteers are often told not to accept gifts from patients because it could later be construed as theft by a family member who did not know the item was given to the volunteer.

Visiting Nurses Association of Atlanta, which includes Hospice Atlanta, runs an Alzheimer's disease respite program for caregivers whose loved ones have not been able to access services and have not been certified as terminally ill. VNA's volunteer training consists of four distinct parts:

- **Program overview.**

Volunteers are introduced to the Alzheimer's Care Program and its volunteer component. The first part of the training outlines other venues in which patients are cared for, such as day care and home health. This part of the training makes it possible for volunteers to pass this information

along to families looking for additional respite care.

- **Patient and family information.**

Volunteers are trained in assessing caregiver needs and getting to know the patient. This helps the volunteer learn how to establish a relationship with the patient and capture information that will help clinical staff when the patient is admitted into hospice. Volunteers are introduced to the program's Participant Highlight Sheet, which prompts them to ask a series of questions about the patient, including where the patient grew up, hobbies, and favorite foods, to name a few.

"It teaches them to be observant," says **Jolita Wainwright**, volunteer coordinator of Hospice Atlanta's Alzheimer's volunteer program. "We ask them to look around the house for things like pictures. Do they see pictures of family around the house or not? This can tell us a lot."

Volunteers are also trained to look out for household features that could lead to falls or injuries and to note them on a prevention checklist. For instance, the checklist requires volunteers to investigate the bathroom for non-slip surfaces and safety rails.

Volunteers also perform nutrition screening using a form that assesses functional status. For example, the form asks a volunteer to circle whether the patient is able to cook and feed self, requires some assistance, relies on the caregiver to prepare food, or relies on the caregiver to both prepare and feed.

- **Role of the volunteer.**

Hospice Atlanta defines the role of the volunteer as follows:

**Purpose:** to ensure that Alzheimer's caregivers on waiting list have access to volunteer support in conjunction with interdisciplinary team and the plan of care.

**Policy:** Volunteer coordinator will assess each patient/family for needs which could be met by a trained volunteer. The volunteer, once assigned to a patient, becomes part of the interdisciplinary team, communicating observations made during each visit.

The volunteer respite provider is trained in establishing an initial relationship with the client, establishing trust, and learning about the impact they can have on the family. They are taught that trust is gained through positive body language, a warm approach, assuring their support of the family, and letting the family know that the volunteer enjoys the client's company.

Patterson stresses that none of these components is sufficient by itself, but together they provide a clear picture of potential risk as well as demonstrating that the hospice has made a reasonable effort to protect its clients from predatory individuals. ■

## Hospitals increase end-of-life discussion

### *Frank talk about death and directives*

One of the main reasons hospices have difficulty promoting themselves is because most people generally choose not to think about death. But there are signs that health care providers outside the hospice industry are trying to communicate with their patients about the importance of planning for the inevitable and coming to terms with a terminal illness sooner rather than later.

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, says **Elaine Glass**, RN, MS, AOCN, clinical nurse specialist at James Cancer Hospital in Columbus, OH. At that time, people should receive literature that explains such intensive care treatments as cardiopulmonary resuscitation (CPR), ventilators, and artificial nutrition and hydration.

The topic of dying is a complicated subject. Perception of end-of-life care varies widely among individuals, cultures, and religions. There is no one-size-fits-all approach to getting the discussion rolling, says **Shirley Otis-Green**, ACSW, LCSW, clinical social worker in supportive care and palliative medicine at City of Hope National Medical Center in Duarte, CA.

Education and support regarding end-of-life issues should not be limited to the times when a terminal illness is diagnosed or when a patient experiences sudden death, Otis-Green advises.

At City of Hope, a new program is being developed to help patients and their family members move through the dying process. The program is called "Transitions: Supporting You Through the Journey of Change." "We are trying to develop a compassionate, caring, comprehensive model that looks at how we can help the person understand by giving them education,

support, and the tools they need,” explains Otis-Green.

In visiting the bedsides of dying patients, Otis-Green has noticed that the biggest difference in the degree of suffering is in the amount of regret the person has experienced in life. For example, one terminally ill patient had lived her life for her children and husband. She knew their favorite colors and foods, but not her own. She had never developed, expressed, or shared her talents, and was therefore experiencing enormous regrets.

“If we live life where we minimize our regret, then we are better able to live a life that might be lengthened,” Otis-Green says.

People can benefit from examining their feelings about death before they are confronted with it. Everyone should address his or her own attitude toward death and how denial, anger, spiritual crisis, and acceptance play roles in our attitudes about death.

City of Hope takes a variety of approaches to education about death and dying issues. 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 and disoriented, it is part of the natural process of dying.

Another part of the program will help people access their own resources. While a daughter may not have lost her mother to breast cancer before, she has dealt with other losses, challenges, and crises, and 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. She can use those learned coping skills to help her deal with her current situation.

The social work department of Deborah Heart & Lung Center in Browns Mills, NJ, provides supportive counseling for patients and family members to help them get past the myths and mysteries of the dying process. “A lot of time is spent on support, just getting them to verbalize their fears and concerns and ask questions,” says **Michelle Goffney**, BSW, MSW, LCSW, director of social services at the medical facility.

Family members often don’t understand the concept of withdrawing life support. Their image usually is one of pulling a plug, says Goffney. It’s important to explain that decreasing ventilator support is a gradual process, accompanied by measures to keep the patient comfortable with medications.

At James Cancer Center, patients are informed early in the process that advance directives will ensure that the patient’s wishes are followed. They’re also told that written instructions will absolve family members from having to make difficult decisions.

### *‘Values history’ states beliefs clearly*

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. That’s why Glass wrote what she refers to as her “values history” in her own advanced directive.

In this document, she states her beliefs on various medical procedures, her attitude about organ donation, her views on health, and thoughts about independence and control. “I comment about not wanting to be disabled and physically limited in my movement,” she explains. It includes her overall attitude about life, her religious background, and her beliefs about God and heaven.

There are other ways to provide pertinent details within advance directives, says Glass. Several years ago, the Journal of the American Society of Certified Life Underwriters published guidelines for making end-of-life decisions in four situations:

- if I were in a coma or persistent vegetative state;
- if I were in a coma and might survive;
- if I had brain damage;
- if I 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.

Detailed written instructions remove any mysteries about the patient’s dying wishes. “A lot of physicians are uncomfortable in trusting families to make decisions that aren’t in writing, because they don’t know if the family is just after their inheritance,” says Glass. ■

# Pediatric end-of-life improvements sought

## *IOM committee begins deliberations*

A new Institute of Medicine (IOM) committee is seeking ways to pay for end-of-life care services for dying children, including possible revisions of the current federal reimbursement regulations.

"The whole problem of reimbursing for children who are in the dying phase of their disease or need palliative care is a real issue," says committee Chairman **Richard E. Behrman**, MD, JD. Reimbursement is only one of the items on the panel's agenda, says Behrman, senior vice president for medical affairs at the Lucile Packard Foundation for Children's Health and clinical professor of pediatrics at Stanford University and the University of California, San Francisco.

## *Panel aims to provide overview*

The project, called Challenges of Providing End-of-Life Care for Children and Families, will study all the factors that influence pediatric end-of-life care. "Our objective is to provide a comprehensive look at what we know and don't know about care for dying children, and what we know about good care that we don't use," says **Marilyn Field**, PhD, senior IOM program officer and study director for the project.

The committee isn't making an explicit point-by-point comparison between end-of-life care for children and adults, but will explore certain parallels. "We're very interested in getting the attention of the critical care community," Field says.

The committee will investigate the extent to which children are admitted to ICUs with a prognosis that death is virtually certain. "We're also looking at the kinds of communication that happen with parents, and when the physician and parents understand that survival isn't expected," she says.

Accidents are the most common cause of pediatric death, and many of these injuries bring children into pediatric critical care units. "The situation appears to be that prognosis for children is often more difficult," Field says. "Their physiology is different, they're more resilient, the major causes of death are different, so it appears they are not as likely to fit the hospice

care definition used by Medicare."

Field observes that the HCFA "six-months-before-death" rule for hospice eligibility that allows reimbursement for palliative care is extremely difficult for critical care physicians to apply. Because predicting life duration is tricky for any patient, even the elderly, many patients are unable to benefit from hospice-type services.

"When the patient is a child, the situation becomes more complicated," Field says, "because parents are often unwilling to completely forgo curative or life-extending care, which is a reimbursement condition in most Medicaid programs."

The study group aims to develop recommendations for increasing access to compassionate and effective care for dying children and their families. The group's work is sponsored by the National Institute of Nursing Research, the Ryan White Program of the Health Resources and Services Administration (U.S. Department of Health and Human Services), and the Open Society Institute.

As presently defined, the committee's charges include:

- describing the major causes of death for children, sites of death, and differences in the dying process for different causes of death;
- assessing the state of knowledge about clinical, behavioral, cultural, organizational, legal, and other important aspects of end-of-life care for children and their families;
- considering methods for measuring care outcomes, determining family and child/patient preferences, communicating information, resolving conflicts, and assessing end-of-life care as experienced by children and their families;
- examining the availability, evidence base, and usefulness of practice guidelines for clinicians who care for dying children;
- proposing a research and action agenda to strengthen the scope and application of the knowledge base for providing effective and compassionate care for dying children and their families.

The committee plans to hold a public meeting in September. "We expect to invite testimony and statements of views from interested organizations," Field says. Written statements from individuals may not receive committee responses due to staff and time constraints, but they can be submitted to: Challenges of Providing End-of-Life Care for Children and Families Project, 2101 Constitution Ave. NW, Washington, DC 20418. Telephone: (202) 334-2310. ■

## E-philanthropy: Reaching new donors

*Use your web site as a marketing tool*

By **Dee Vandeventer**  
Mathis, Earnest and Vandeventer  
Cedar Falls, IA

If you're looking for another way to connect with potential donors but don't want to send out another brochure or organize a special event that will be only moderately successful, don't overlook e-philanthropy.

E-philanthropy involves using the Internet to give possible donors another giving option. In addition to the usual methods of donation solicitation, many philanthropic organizations have web sites that allow potential donors to receive information or make a pledge.

According to the Jan. 25, 2001, issue of the *Chronicle of Philanthropy*, there are several reasons donors don't give on-line:

- the giving option isn't offered;
- there is inadequate information to make a decision;
- the donor is uncomfortable about giving out credit card or other personal information over the Internet.

Many donors are just now deciding to make their first on-line contribution. Donors will expect your organization to maintain the highest standards of ethics, privacy, and security to ensure their on-line giving experience is a positive one.

Before you jump into the deep end of the e-philanthropy pool, here are some life preservers to keep you afloat:

- **Establish your e-brand.** If you build it, they might not come; you have to build it well. Building an on-line brand is just as important and as difficult as building on off-line brand. People should be able to discover you, understand who you are, and contact you. Brand building on the web means defining your role in people's lives.

- **It takes know-how and vision.** You need to see your organization's web site as a marketing, communication, and fundraising tool. When you set up a web site, you take on the responsibility

of using the tool; if you don't use it correctly, you won't see any returns from it. Part of your responsibility is communicating with those who use your site and changing the site to serve their needs.

Keeping your site up to date and clean tells your audience three things:

- your organization knows what it's doing;
- you're worthy of being taken seriously;
- you've taken the time to think through the needs of your users.

It's crucial that you provide updated content that has enough appeal to make people want to come back to your site. This applies to links pages as well. It is important that you check links regularly to make sure they are functional. The payoff is that your audience becomes or remains your customer.

- **Know your site's target audience.** Who are your current and potential contributors, and what do they need? Your web site's content should be driven by what your audience needs most.

- **Follow through.** Make on-line giving easy, give the donor options, use the latest technology, and show your donors how their funds are being used. Following through also means making your web site accessible and easily navigable as well as using the site to give people more than one option for responding to you, such as e-mail, an electronic form that can be filled out, an 800 number, and snail mail.

Once you've heard from people, let them know you're there and you're listening. Get back to them pronto by phone or e-mail and keep them updated on what's happening with your organization. These things will ensure they come back to your site.

- **Integrate your web presence into everything you do.** Your web site alone will do nothing. Every activity should drive traffic to your site. Incorporate your web address on all materials, and target web audiences through publications, web portal sites, and web directories. Word of mouth, search engines, traditional advertising that features your web address, news and magazine articles, and links from other sites are all key ways to get people to visit your site.

According to the Mellman Group's report for Craver, Mathews, Smith (September 1999), word of mouth is the most frequent method (34%) of driving traffic to charitable web sites. Search engines and traditional ads that include site addresses come in second and third, respectively

(33% and 31%). The least effective method is receiving information from the sponsoring organization (11%).

• **Don't trade your mission for a shopping mall.** Many nonprofit web sites fail to emphasize their mission, instead turning themselves into online shopping malls. By then, it's too late and potential donors have gone elsewhere.

• **e-philanthropy is not a quick fix for your fundraising woes.** e-philanthropy is a tool to be used in your fundraising strategy; it should not be viewed as quick money or used in place of your other fundraising efforts. There are no shortcuts to building effective relationships. But the Internet is one more way for you to build a community of supporters for your mission.

Remember one of the central tenets of giving:

People give to people. Creating and maintaining a web presence should enhance — not hinder — good relationships with current and potential donors.

*[Editor's note: To learn more about e-philanthropy, visit these web sites:*

[www.e philanthropy foundation.org](http://www.e philanthropy foundation.org)

[www.philanthropy.com](http://www.philanthropy.com)

[www.charitychannel.com](http://www.charitychannel.com)

[www.craveron-line.com](http://www.craveron-line.com) (*Landmark Study of ePhilanthropy*)

*Dee Vandeventer is president and partner of Mathis, Earnest and Vandeventer, a fund-raising and integrated marketing communications consultancy in Cedar Falls, Iowa.] ■*

## News From the End of Life

### VA picks care sites for end-of-life project

The Department of Veterans Affairs (VA) has selected six health care sites to launch its new program focused on changing the way physicians, social workers, nurses, and other caregivers approach end-of-life care.

The initiative, called "VA Interprofessional Fellowship Program in Palliative Care," will foster the development of health care professionals with vision, knowledge, and compassion to lead end-of-life care into the 21st century. Although aimed at improving care for veterans, the program will affect how palliative care in medical circles is provided throughout the country.

The following VA health care sites were selected from among 21 that applied: Bronx, NY; Los Angeles; Milwaukee; Palo Alto, CA; Portland, OR; and San Antonio.

Each site will have four one-year fellowships or equivalent part-time positions. Palo Alto will

serve as the hub site and will be responsible for coordinating curriculum, program evaluation, educational outreach, and recruitment strategies.

"This program is one of the most important developments in the field of palliative care," says **Susan Block**, MD, chief of adult psychosocial oncology at the Dana Farber Cancer Institute at Harvard Medical School and Brigham and Women's Hospital in Boston. "The fellowships will train a cadre of expert clinicians who will serve as beacons for others interested in improving care at the end of life throughout VA and the country."

The new fellowship program has a large educational component. Trained clinicians are expected to serve as leaders promoting development and research. Selected training sites will be required to develop and implement an "Education Dissemination Project" to spread information beyond the training site through conferences, curricula for training programs, patient education materials, and clinical demonstration projects.

As resident doctors go out into the community, they take their training with them. More than 130 VA facilities have affiliations with 107 medical schools and 1,200 other schools across the country. More than half the physicians practicing in

### COMING IN FUTURE MONTHS

■ Reimbursement support for referring physicians

■ Community awareness projects

■ Making managed care work

■ Caregiver outreach programs

■ Hospice information on the Internet

the United States have received part of their professional education in the VA health care system.

“There comes a time when all the modern medicine in the world can’t cure the illness. That’s when treating the pain, communicating with compassion, and providing support and counseling become paramount. And that’s what these fellowships are all about,” says **Stephanie Pincus, MD**, VA chief officer for Academic Affiliations. ▼

## New book documents dying first-hand

Living with a terminal illness and caring for someone who is dying is difficult. But a new book, *Few Months to Live: Different Paths to Life’s End*, focuses on the endurance of the human spirit at the end of life.

The book is the result of a study conducted by the Missoula Demonstration Project. Authors **Jana Staton, Roger Shuy, PhD, and Ira Byock, MD**, offer a glimpse of the lived experiences of everyday people who faced life’s end, experiences captured in the words of patients and families who have gone through the dying process and who agreed to be study participants.

Staton is the author of “Listening to Families,” an ethnographic series of 11 videotapes and study guides for personnel working with families who have very young children with disabilities. Shuy is author of *Bureaucratic Language of Government and Business* and is Distinguished Research Professor of Linguistics Emeritus at Georgetown University in Washington, DC. Byock, a research professor in the department of philosophy at the University of Montana in Missoula, is cofounder and principal investigator of the Missoula Demonstration Project and is the author of *Dying Well: Peace and Possibilities at the End of Life*.

In the book, the authors introduce readers to Dennis, a young man suffering from a rare form of cancer, and his mother, Carrie. “It seems we are just chasing fires, stamping out fires,” Carrie says of her days alone managing Dennis’ care. “Just eating, pain control, and sponging. That’s it.” The vignette includes a 60-mile trip with Dennis and Carrie as they make their weekly drive from their rural home to Missoula where Dennis receives treatment, including pain control, which is complicated by Dennis’ insistence on maintaining his coherence.

The authors allow the words of all of these people to illustrate how dying people communicate, describe how or if they plan for the inevitable, recall what their doctors and nurses said to them, and describe how they understand their illnesses.

But it is the two chapters on caregiving that bring home one of the book’s major findings: Informal caregiving by relatives and close friends is an enormous, often overwhelming, months-long task that society neither properly recognizes nor supports. “Caregivers finished their work exhausted and deprived of any social life or activities outside the home,” the authors write. “Some felt guilty for not having done their jobs even better.”

Despite these realities, the authors also showed how caregivers persevered. “I decided some months ago that we just couldn’t leave her alone anymore,” says one caregiver who cared for her sister. ▼

Hospice Management Advisor™ (ISSN# 1087-0288) is published monthly by American Health Consultants®, 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. Application to mail at periodical rates is pending at Atlanta, GA 30304. POSTMASTER: Send address changes to Hospice Management Advisor™, P.O. Box 740059, Atlanta, GA 30374.

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### Editorial Questions

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

# Canadian Pain Society launches 'manifesto'

In July the Canadian Pain Society released the Patient Pain Manifesto in hopes of raising public awareness about pain management rights.

"The Patient Pain Manifesto was developed by the Canadian Pain Society [CPS] as a 'Bill of Rights' to clearly communicate to hospital patients and their families their rights regarding treatment of pain resulting from surgery, treatments, or illness," says **Celeste Johnston, MD**, president of CPS and professor in the School of Nursing at McGill University in Montreal.

"Studies show that a surprising number of patients believe that suffering is part of being in hospital and being ill," Johnston notes. "We want to make sure that patients with pain are fully aware that they have the right to receive treatment that will keep their pain under control and help them reclaim their lives."

## *Viewing pain as a treatable condition*

Awareness and education are of primary importance in pain management. Patients need to know pain is a medical condition that can — and should — be treated, just as infection, diabetes, or high blood pressure are treatable, says Johnston.

Health professionals can't treat a patient's pain until the patient or his or her family reports the type and level of pain. The CPS Patient Pain Manifesto gives them a tool for doing this. Health professionals then have a responsibility to assess pain routinely, to believe the patients' pain reports, and to help prevent the pain, the CPS maintains.

Goals for the future of this national educational and awareness initiative by the Canadian Pain Society include:

- Ensure adequate education of medical and nursing students during their training.
- Provide more continuing education opportunities to health care professionals on the assessment and management of pain.
- Work more closely with patients to determine areas of need.
- Work more closely with industry to market educational materials.
- Distribute 1,000,000 bookmarks to patients, their families, and health professionals.
- Distribute 10,000 posters to health care professionals and clinics. ▼

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## Alzheimer's caregivers face a grim outlook: Study

A five-year study of Alzheimer's patients and their families show that caregivers are more likely to be hospitalized and are three times more likely to become clinically depressed than others in their age group. Elderly spouses who are caregivers are 63% more likely to die than other spouses of the same age.

Results of The Dementia Care Project were released to a group of geriatric and health care professionals in July by Kaiser Permanente and the Alzheimer's Association Los Angeles. The results highlighted the importance of physician guidelines, early diagnosis, a case management model, and caregiver support.

Alzheimer's Association surveys indicate that 19 million Americans say they have a family member with the disease. The Alzheimer's Association Los Angeles and Kaiser Permanente developed guidelines for the diagnosis of Alzheimer's disease. They later adopted post-diagnostic care guidelines, trained primary care providers and social workers in dementia care, and hired and trained two Kaiser Permanente care managers to work specifically with dementia families and their physicians. ■