

# HOSPICE Management ADVISOR

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## Reach caregivers before loved one is eligible for hospice

*Community education programs, training needed for legions of Americans*

Caring for a dying or chronically ill loved one at home is a labor of love that goes largely unnoticed by the rest of society. Caregivers sacrifice careers, time with other family members, and even their own identities to fulfill a promise of unconditional love. Yet despite their heroism, the rest of the world not only fails to recognize their efforts but has also abandoned them.

“Caregiving is a hidden activity in America,” says **Suzanne Mintz**, president and co-founder of the National Family Caregivers Association in Kensington, MD. “All people see are media images of thin, healthy people, and they don’t want to see people who are ill and need help.”

An estimated 25 million people, mostly women, are caregivers. They care for their frail, elderly parents and for chronically ill spouses. Eventually, many of these caregivers continue on as the custodians of their loved ones as they go through the dying process. And for the few who choose hospice, it isn’t until then that caregivers are paid the attention they deserve.

The real number of caregivers is closer to 50 million, according to the National Family Caregivers Association. The association surveyed more than 1,000 people last year and discovered that more than 26% had taken on caregiver responsibilities in the previous 12 months.

Whatever the number, Mintz believes hospices should play a larger role in providing caregivers with the help they need when they need it most: before the patient is admitted to hospice.

“Let’s face it, by the time the patient is admitted to hospice, they have just a few weeks — sometimes a few days — before the patient dies,” says Mintz. “That’s too little time to be of any help to the caregiver.”

Mintz says hospices can help caregivers through bouts of low self-esteem and isolation and can provide programs to educate them on the daily routine of caregiving. Most importantly, hospices can help educate

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caregivers on the medical needs of the patient so caregivers can not only perform the daily duties of caring for a loved one but can also act as an advocate for the patient. For example, hospices can use this opportunity to help caregivers and patients establish an advance directive, a power of attorney, or a living will so caregivers can make sure their loved one's wishes are followed.

### **Combat stress**

Even before caregivers receive care from hospice workers, they are burdened by a myriad of factors, including:

- **Physical stress.** The host of responsibilities that go along with caring for a loved one can take a physical toll. General homemaking and house-keeping activities such as cleaning, laundry, shopping, and meal preparation require energy and can be tiring, particularly when added to existing responsibilities in one's own home.

In addition, personal care required for the supervision of medications and the maintenance of hygiene also can be stressful, particularly in situations of acting-out behaviors, incontinence (loss of bladder or bowel control), colostomies, or assistance with bathing. Lifting and transferring individuals with limited mobility is not only tiring but also can result in injury to the caregiver or the impaired person. In some instances, there is the additional responsibility of maintenance of equipment such as wheelchairs or hospital beds.

- **Financial stress.** When money is limited, many families assist with the cost of care, causing financial burdens on all family members. Often, the sick person was the sole provider or contributed largely to the household's income. The lost income causes financial uncertainty on top of other stressors.

- **Environmental stress.** For people who choose to care for their loved ones at home, their home environment can cause undue stress because homes are ill-equipped as health care facilities. If the patient elects to remain in his or her own home, modifications such as railings and ramps may have to be installed. If the patient cannot remain in his or her own home, alternative arrangements must be sought, such as moving in with a friend or relative or specialized housing (retirement hotels, senior apartments, residential care homes, intermediate care facilities, or nursing homes).

- **Social stress.** Caregivers who provide personal care 24 hours a day can experience social

stress through isolation. Caregivers may find themselves too tired or unable to have personal time with family and friends. What can result is a build-up of anger and resentment toward the person receiving the care.

- **Emotional stress.** All of the above factors often result in tremendous emotional stress. Compounding these sources of stress are the difficulties in managing one's time, juggling multiple responsibilities, and feeling the pressure of the patient's increased dependency.

The Hospice of the Florida Suncoast in Largo, FL, provides a number of caregiver outreach programs based on the assumption that caregivers are in need of help before they become eligible for hospice care.

Among them is a series of evening classes aimed at providing education on the mechanics of caregiving, such as how to lift patients out of bed; patients' physical and emotional needs; living wills and durable power of attorney; and community support programs.

Still, it's difficult to get people to attend such classes, says **Becky McDonald**, RN, vice president of programs for the Hospice of the Florida Suncoast. "People come and go so rapidly, taking care of their loved ones," says McDonald. "They don't take any time away from the person they are caring for."

For that reason, McDonald says, programs that work on a one-on-one basis with caregivers work best. In addition to its community service classes, the hospice also has developed a palliative care program using a sliding-scale fee-for-service model to cover the cost of care.

The Suncoast Palliative Care program features a nurse practitioner case manager and an interdisciplinary team that provide care to patients who have shown a functional decline and whose physicians have diagnosed them with no more than two years to live. Aside from the care given to patients, the program also focuses on the caregiver by providing respite care and education.

Hope Hospice and Palliative Care in Fort Myers, FL, offers a number of programs, as well. "Our hospice is looking at how to get to caregivers sooner," says **Samira Beckwith**, CHE, ASW, president of Hope Hospice and Palliative Care. "One of the essential core services of hospice is caring for the caregiver."

Hope Hospice's caregiver services include:

- inpatient and outpatient respite care;
- extending alternative therapies (such as massage, music, and art) to the caregivers;

# Caregiver training manual available

A new manual aimed at helping the millions of caregivers who need assistance and information has been developed as part of a joint project between a pharmaceutical company and a host of nonprofit groups.

The manual, titled *Caring to Help Others: A Training Manual for Preparing Volunteers to Assist Caregivers of Older Adults*, consists of more than 500 pages of information organized and written in a user-friendly style. Topics include the aging process; age-related health conditions and challenges; the need for sensitivity, understanding, and respect for older adults; how to work effectively with a team of family caregivers and professional health care providers; legal and safety issues; and dealing with relationships and the loss of loved ones. It contains several useful tools for trainers, including handouts, exercises, and guidelines for recruiting volunteers and forms for record keeping.

The manual is available free of charge to qualified organizations with training programs for volunteer support caregivers or plans to begin one. The comprehensive training manual was produced for organizations that train volunteer caregivers. It was created by nine nonprofit organizations with expertise in aging, health care, and caregiving. The manual's production was sponsored by Eisai Inc., a research-based pharmaceutical company in Teaneck, NJ.

"I salute Eisai and the organizations that created this manual for helping to assure high-quality training for volunteer caregivers," said

- community caregiver training classes;
- caregiver support groups;
- a volunteer respite program.

Mintz says caregiver support groups are particularly important. In addition to offering useful information, such groups provide a unique forum for caregivers to come together and share their feelings in a supportive environment. Group therapy helps caregivers feel less isolated and can create strong bonds of mutual help and friendship.

Participating in a support group can help caregivers manage stress, exchange experiences, and improve skills as a caregiver. Sharing coping strategies in a group setting lets caregivers help

**Kenneth Hicks**, chairman of the board for Interfaith Caregivers Alliance (IN CITY, STATE). "Caregivers are truly special people. It is an exhausting job, and volunteers can provide much-needed respite to primary caregivers, as well as care for older adults who have no family or friends to act as primary caregivers or who simply cannot afford the cost of professional care."

Hicks added that a comprehensive training resource was needed as a result of the growing number of caregivers in America. Between 1988 and 1996, the number of U.S. households with caregivers tripled to about 22 million. In 1997 alone, it was estimated that unpaid caregivers provided the equivalent of \$196 billion in care.

Caring to Help Others was developed by an advisory council of representatives from top caregiving advocacy groups, including: the American Association of Retired Persons, the Interfaith Caregivers Alliance, the National Alliance for Caregiving, the Hospice Association of America, the National Association for Home Care, the National Council on Aging, the National Family Caregivers Association, the Towson University department of gerontology, and the Alzheimer's Association, Greater New Jersey Chapter.

The manual is available free of charge to qualified organizations for training volunteer caregivers. Organizations that meet the established qualification criteria may request free copies of the training manual by writing on their letterhead to: Caring To Help Others, P.O. Box 5376, New York, NY 10185-5376. The manual also will be available on a Web site later this year. ■

others while helping themselves. It may also help caregivers to realize that some problems have no solutions and that sometimes simply accepting the situation is the best thing to do.

Emotional isolation is often coupled with physical isolation that prevents caregivers from learning about community services. Hospice must provide information about community resources that might be helpful. Caregivers will likely seek assistance from in-home services or adult day care; homemaker services to help with cooking and cleaning; or an aide to help the patient bathe, eat, dress, use the bathroom, or get around the house.

Of course, the burden of fulfilling these tasks requires an escape from time to time. Respite care can help caregivers get away for a short time or accomplish tasks that have been put off in lieu of more important matters.

Hospices do not have to be the sole providers of respite care. Hospitals, nursing homes, and residential care facilities could offer families the opportunity to place older relatives in their facilities for short stays.

Aside from practical help, hospices can provide the skills and advice to help caregivers cope with the challenges that lay ahead of them, says Mintz. For instance, caregivers need to know how to set realistic goals, as well as how to seek help when they can't reach those goals. Teach caregivers to recognize their limitations and define their priorities. For example, help them prepare a list of tasks — running errands, meal preparation, taking the patient for a walk, taking children to and from school — and a list of family, friends, and community services that can assist in completing these tasks.

Caregivers also need help communicating their needs to family, friends, and the loved one they are caring for, says Beckwith. Often, family dynamics that existed prior to an illness can hamper communication, or the illness may have reduced contact with the caregiver. Turning to family members or friends for emotional support and help can be a mixed blessing. Visits from these people may cause the caregiver to feel less alone and more able to deal with caregiving responsibilities. On the other hand, relatives or friends can be critical of the way the caregiver is providing care. Caregivers need to be made aware that these family members are responding to what they see at that time and are lacking the benefit of experiencing the whole picture and any gradual changes in the patient's condition. Harsh criticism may be a response to their own guilt about not participating more in the care process.

Another key factor in a caregiver's ability to cope is the caregiver's ability to maintain his or her health. Hospice caregiver training should stress the following:

- eating three balanced meals daily;
- exercising daily;
- getting enough sleep/rest;
- allowing sufficient leisure time.

All this education and training must be given long before a patient becomes eligible for hospice care, says Mintz. Even if a patient lasts two months in hospice care after battling a chronic

illness, such as Alzheimer's disease, the benefit of caregiver education is muted.

"Former caregivers have already gone through the challenges that a hospice is addressing," says Mintz. "They are likely to say: 'I've spent so much time going through all this, what do I do with all this information now?'" ■

## Consider extending bereavement care

*Grief likely to last more than a year*

After a patient dies, the focus of hospice work turns to family and friends who are left to grieve. For the next year, social workers and chaplains must help those who are left behind to pick up the pieces and move on.

For some, this yearlong episode of care is enough to get them back on solid ground. But for many, a year is not enough. Depending on a number of factors — including the length of illness, caregiver responsibilities, and the relationship of the deceased to the survivor — grief can last years. Often, grief never goes away.

Studies on how people grieve bear this out, as well. The body of work on grief points out clearly that healing following the death of a loved one is not a function of time, but is dictated by a host of factors that are unique from one individual to the next.

"I'm coming on the 10th anniversary of my children's death, and it's bringing back some old emotions," says **Patricia Loder**, executive director of Oak Brook, IL-based Compassionate Friends, an organization that supports parents whose children have died.

Bereavement care is an integral part of the hospice mission, but Medicare does not reimburse hospices for the countless hours of counseling. Because the care is provided for free and costs are not recouped, most hospices must put a time limit on this care. That is at odds with the one-year follow-up bereavement care that most hospices offer to families.

Two factors are important in recovering from grief: time and emotional support from others, writes **Lewis R. Aiken** in his book *Dying, Death, and Bereavement*. "Feelings of grief are a natural reaction to any loss, but the duration and intensity

of these feelings vary with who or what is lost and when the loss occurs," he writes.

Once a survivor completes a one-year hospice bereavement program, those two important factors are suddenly absent, especially for those who do not have family or friends to turn to. The next year, survivors are left alone to face important dates, such as the death anniversary, wedding anniversary, birthdays, and other significant dates.

"For many, the second year is worse than the first year," says Loder. "That's why I'm against any program that is based on time."

Hospices that currently offer one year of bereavement care should consider extending care beyond the traditional length of time, says **Sherri Weisenfluh**, LSW, MSW, associate vice president of counseling for Hospice of the Bluegrass in Lexington, KY. Rather than 12- or 13-month programs, Weisenfluh says hospices should manage grieving people using a continuum of care, such as individual counseling, group sessions, and community programs, with the most intense period of care coming in the first and second year. Follow-up visits, calls, and/or community program referrals should be used over the next few years.

The bottom line, says Loder, is that people should not be made to feel as if their emotions are illegitimate simply because they continue to grieve beyond what people think is an adequate amount of time to grieve.

Of course, there are grief symptoms that are to be expected. Early on, feelings of confusion, loneliness, embarrassment, or discomfort expressing grief, and even a desire to join the loved one in death are all normal expressions of grief.

"If a person is left alone after a year, still having these emotions, it's easy for them to feel as if they are not grieving right," Loder says. "They need to know that it is okay and that they are allowed to feel the way that they do."

The challenge for hospices is to provide adequate bereavement care to everyone irrespective of time and to do it in a way that does not create an undue burden on a hospice's financial and personnel resources.

Weisenfluh is sensitive to the limited resources of most hospices. Hospices that are large enough or wealthy enough should extend their bereavement programs to allow for routine visits for longer than a year. In addition, those same hospices also should allow social workers to have regular contact beyond two years.

For the first two years, those suffering from grief should be exposed to the following:

- **Group-oriented bereavement counseling.** Isolation and guilt are among the emotions the bereaved endure. Group counseling provides the understanding and support from others than may be missing. In addition, the support of those who have gone or are going through the same process can help those grieving the loss of a loved understand their own emotions and feel normal.

- **Individual grief counseling.** Group counseling can be an efficient way to counsel more than one grieving person, but many people need individual counseling to deal with the emotions surrounding their grief.

- **Community services.** Nonprofit groups like Compassionate Friends exist in many communities. Hospices should be aware of the available services that could benefit the survivor.

In addition, a hospice should make provisions for follow-up care in the future. Weisenfluh recommends that hospices create a follow-up schedule for each of the patients who go through its grief programs. Depending on the circumstances of each case, social workers can decide for how long the hospice should follow up.

Wedding anniversaries, death anniversaries, birthdays (both the survivor's and the deceased), and the holidays are obvious dates that should prompt a phone call from the hospice to gauge emotional stability and whether a visit or referral is warranted.

How long this type of follow-up care should continue is survivor-dependent, Weisenfluh says. An elderly widow will likely need less extended follow-up than a 12-year-old girl whose father died. The young girl may have resolved her emotions as a pre-teen, but may face an entirely new set of emotions when she reaches other milestones, such as graduations and her wedding.

### ***Spotting troubled cases***

Still, there will be hospices that cannot afford to allocate so many resources for such a long time. Instead, their goal should be not only to treat current emotional symptoms, but also to assess the bereaved person's potential for prolonged grief and provide the needed information to help them recognize when they need help and where to get that help.

Indications of complicated grief or the possibility that surviving friends or family members will experience chronic grief include:

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

- **Unrelenting anger and hostility.** The survivor cannot engage in 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 person feels isolated and alone.

For those who are having a more difficult time processing their grief, treatment might include not only grief counseling but also grief therapy to help facilitate a more timely resolution. The goal of grief therapy is somewhat different from the goal of grief counseling. The goal in grief counseling is to facilitate the tasks of mourning in the recently bereaved to facilitate the bereavement process and provide a successful termination.

In grief therapy, the goal is to identify and resolve the conflicts of separation that preclude the completion of mourning tasks in people whose grief is absent, delayed, excessive, or prolonged. Grief therapy is most appropriate in situations that fall into the following three categories:

- **The complicated grief reaction is manifested as prolonged grief.** People who have this difficulty know they are not coming to an adequate resolution of their grief, because the loss has occurred many months (sometimes years) earlier. The reason behind this type of complicated grief reaction often is a separation conflict leading to the incompleteness of one of the tasks of grieving. Much of the therapy involves trying to discover grief tasks that have yet to be completed and learning what prevented them from completion.

- **The grief reaction manifests itself through some masked somatic or behavioral symptom.** These bereaved persons are usually unaware that unresolved grief is the reason behind their symptoms. However, a peripheral diagnosis reveals unresolved grief over a much earlier loss

as the culprit. People usually experience this kind of complicated grief reaction because, at the time of the loss, the grief was absent or its expression was inhibited. Consequently, their grieving was never completed, and this caused complications that surfaced later as somatic or behavioral symptoms.

- **The reaction is manifested by an exaggerated grief response.** A precise definition of exaggeration is difficult because of the wide variety of manifestations that normal grief can take, but persons falling into this category would be those with excessive depression, excessive anxiety, or some other feature usually associated with normal grief behavior manifested in an exaggerated way so that the person is dysfunctional and a psychiatric disorder diagnosis could apply.

In addition to preparing survivors for the years after the first year of grief, hospices also should educate surviving family members and friends about services available to the community, perhaps even referring them to programs before the year is up to ensure a smooth transition

“Hospices need to teach [bereaved people] to teach other people what they need,” says Loder. “[Bereaved people] need to be taught that it’s okay to still be grieving years after they have lost someone they love.” ■

## Tips for raising the fundraising bar

*Which type of campaign suits you?*

**F**undraising is a Catch-22 proposition. In order to raise money, a hospice has to spend money, and sometimes even lose money. The fiscal questions that hospices must answer year after year are whether they are spending enough to raise money and whether they are getting the best return on their investment.

The ability to raise money can mean the difference between a hospice being able to meet its year-end goals or having cut back on programs. That’s why experts advise that hospices approach fundraising not as an annual ritual but as a financial resource just like Medicare and other payers.

That means looking at the way you raise money with the same diligence you any other income source. When hospices evaluate care

and reimbursement, they compare costs of care to reimbursement. The same approach should be used when evaluating fundraising efforts. Hospices must determine which type of fundraising will bring the greatest return based on the hospice's fundraising goals, its current financial position, and its fundraising efforts.

The two most common types of fundraisers for hospices are direct mail solicitation and special events. The two, however, should not be considered interchangeable. Each should be used under the appropriate conditions to ensure the hospice is getting the best return for every dollar it invests.

Other avenues for fundraising include:

- personal solicitations;
- sales of goods and services;
- requests for donations from corporations or foundations;
- planned gifts.

"It really depends on the organization," says **Daniel Shelles**, a consultant with Sinclair, Townes & Co., an Atlanta-based public relations firm that provides fundraising advice to nonprofit organizations, including hospices. "It's hard to say whether direct mail is better than special events because every organization is different."

Hospices must consider their current needs, says **Dee Vandeventer**, MA, president and partner of Mathis, Earnest & Vandeventer, a Cedar Falls, IA-based public relations firm that consults with hospices on fundraising.

"When I advise hospices, I look at their resources and whether they are visible in the community," Vandeventer says.

### ***Building a donor base***

The fundraising model looks like a pyramid, Vandeventer says. The tip of the pyramid represents the prized but small population of big contributors, and the lower section represents the base of small contributors that is so important to a successful fundraising strategy.

On the other hand, the effort to raise money is an inverted pyramid. The bottom tip represents the least amount of time and money that should be expended. The widest, highest portion represents the most effort and resources. Side by side, the two pyramids illustrate where hospices should be spending their time and resources — the smallest amount with the base of donors who contribute \$100 or less and the most time in cultivating large donations from corporations and estates.

This, however, represents a hospice with a mature fundraising program. Direct mail fundraising allows hospices to focus on the base of the fundraising pyramid. Although the base is made up of contributors who have donated small amounts of money, the hope is that they will move up the pyramid by contributing larger amounts in the future.

The trick to meeting your fundraising goal is to decide what amounts constitute major, medium, and small gifts, and how many gifts you need at each level of the pyramid. For example, say you need to raise \$300,000 and you decide that \$5,000 or more is a major gift, \$1,000 is a medium gift, and \$50 is a small gift. In that scenario, you need at least: \$100,000 from major gifts, or 20 people or organizations donating \$5,000 each; \$100,000 in medium gifts, or 100 people or organizations giving \$1,000 each; and \$10,000 in small gifts, or 2,000 people or organizations donating \$50 each.

For young hospices and smaller hospices that are trying to build a base of donors, direct mail — written solicitation mailed to potential donors — is the most cost-effective fundraiser, according to Vandeventer. Expansion of a hospice's donor base is required before a hospice can focus on raising money through special events and soliciting larger donations. For hospices in the position of starting from near scratch, the money and effort needed to stage a special event would far exceed the money that could be raised.

Because hospices with small donor bases must focus on increasing the number of donors, direct mail may not yield profits right away. Instead, the exercise is the beginning of a long-range fundraising plan that includes special events that not only raise money but also increase visibility, says Shelles.

The bulk of the cost for direct mail campaigns lies in printing and postage. If a hospice does not have a database of names — past donors, families that have had loved ones treated in their hospice, and volunteers — it will have to incur the additional cost of purchasing a list of potential donors.

Vandeventer says results from direct mail can vary widely. In some instances, a hospice may see as little as a 1% response (one donation for every 100 letters sent) or as high as 85%. She says hospices trying to build their donor bases should expect to lose money, but they should view that loss as an investment. The goal at this early stage of a hospice's fundraising strategy is to expand the base of donors. This base will

provide the seeds for future campaigns and larger donations.

To get the maximum response rate, hospices should send their direct mail packages to those who are most familiar with their organization. Fundraising is a grass-roots effort. The easiest place to start is with family, friends, and business contacts of each member of the fundraising team. Each member should think about where his or her personal contacts fit into the fundraising pyramid — major, medium, or small contributors. They also should look at their contacts' abilities to not only make a contribution but to raise money from their own relationships.

Small or young hospices are not the only ones that could benefit from direct mail. According to Vandeventer, hospices lose an average of 20% of their donors each year. If a hospice has neglected its donor base over a long period, it may have to focus on rebuilding it.

Special events, such as volunteer dinners or memorial programs, raise community awareness and are aimed at prompting larger donations from a smaller group of people. "I'm an advocate of a special event when you are trying to expand your image in the community," says Vandeventer.

Shelles agrees. Direct mail does little to increase community awareness, he says, but events that increase community awareness will contribute to the growth of a hospice's donor base. "Raising awareness spreads the message to other potential donors, which equals more money raised," Shelles adds

### ***Move up to special events***

Hospices that have a strong base of donors can focus on moving those donors closer to the top of the pyramid by building on their past support and asking for a higher amount.

But many hospices already have established fundraising events and may rely more on those to raise money than on personal solicitations. Personal solicitations, while simple, can be a powerful form of fundraising for hospices.

Special events can be time-consuming to plan and execute, says Vandeventer. In addition, the cost could far outweigh the financial benefit.

"It's a great way to get the hospice message out," says Vandeventer. "You can get valuable public exposure. There is a downside, however. The amount of time spent vs. the amount raised is often inverted."

Both Vandeventer and Shelles say that for hospices to get the most out of their event fundraisers, they should secure corporate sponsorship to cover the cost of the event so ticket sales and donations will go straight to the bottom line.

Events have the ability to bring in new donors, but their real value is in promoting or reinforcing the hospice message. People who otherwise would not have contributed may be touched by the emotion present at the event, or past donors may be inspired to donate larger amounts.

Events address donor levels above the base. They allow hospices to cultivate repeat donors. Events should stimulate a sense of ownership among donors. "People give to people," says Vandeventer. "Sure, they are giving to an organization, but they are giving their money to help others. You need to show them how their money is helping others."

Vandeventer says hospices should offer larger donors a seat on the board to further nurture a sense of ownership. Major donors are often solicited by other charities. If you place these donors on your board, you can create a greater attachment to your hospice than to other charities that are competing for the donor's money.

Perhaps often overlooked is the need to thank donors. All donors should receive a "Thank you" letter, with major donors receiving a personal thank you from a volunteer or the administrator of a hospice.

"Thank them in a timely manner," advises Vandeventer. "You should plan to give the appropriate 'thank you' based on the gift."

Aside from recruiting annual donors, hospices also should solicit estates or planned gifts, which are assets set aside in an estate for the hospice upon the benefactor's death.

A planned gift must be evaluated not only on the basis of the impact it will have on the hospice, but also how it will benefit the donor. A full-service program for planned giving offers a wide range of options to potential donors. This kind of program can be very technical in nature and requires a significant amount of legal expertise.

Planned gifts fall into three basic categories:

- bequests or outright gifts;
- invested funds, with the principal going to the charity and the investment income going to the donor or the donor's family;
- invested funds, with the principal reverting to the donor and the investment income going to the charity.

Charitable trusts are generally more complicated forms of planned giving. Depending upon the type of trust involved, the hospice recipient may receive income payments from a trust for a predetermined number of years. At the end of that time, the assets are returned to the donor. In this case, the income from the trust benefits the nonprofit, and the donor retains the principal.

For the smaller nonprofit hospice, some of these more complicated arrangements may be too ambitious. But no organization is too small to get started with the simpler options. At the very least, consider adding a line to your newsletter stating that you accept bequests. Contact attorneys in your area to let them know of your interest. Start with the simplest options and add others as you are able.

As hospices plan their fundraising strategies, they should understand how all these options play a role in their overall fundraising strategy. It's not sound strategy to use direct mail alone or to use events alone. Once a donor base is established, direct mail can be used in conjunction with event fundraisers. The two can address both the need to spread the hospice message as well as the need to maintain a solid base. ■

## News From the End of Life

### JCAHO now monitoring new pain initiative

*Experts applaud new measures*

The Oakbrook Terrace, IL-based Joint Commission on Accreditation of Health Care Organizations (JCAHO), which accredits most of the nation's hospitals and thousands of other health care organizations, has begun monitoring how well these facilities assess and treat pain, marking another positive step toward recognition of the need for better pain management.

The new pain management standards are included in the 2000-2001 Joint Commission standards manuals, and JCAHO surveyors have begun assessing compliance since they took effect Jan. 1. JCAHO's new pain management standards were welcomed by clinicians, pain experts, patients, and

their families who have seen pain go untreated or undertreated for decades.

"These changes have the power to improve the quality of life for millions and millions of Americans," said **June L. Dahl**, PhD, professor of pharmacology at the University of Wisconsin Medical School and president of the American Alliance of Cancer Pain Initiatives (AACPI). "This is a great victory for cancer patients in particular, whose pain is often undertreated. Many caregivers, particularly those involved in cancer treatment, have been challenging health care leaders for years about the need to assess and treat patients' pain better."

Under the new JCAHO standards, patients should be asked about pain and the intensity of the pain, including rating it on a simple zero-to-10 scale. Doctors and nurses will be expected to treat the patient's pain and continue to assess treatment during and after hospitalization.

Studies show that an estimated 70% of people with cancer experience significant pain, while fewer than half receive adequate pain treatment. Fifty million Americans suffer from chronic pain, and four out of 10 people with moderate to severe chronic pain do not receive adequate relief.

"The standards acknowledge that pain is a condition that needs explicit attention," said **Carole Patterson**, MN, RN, director of the Standards Interpretation Unit of JCAHO. "Research shows that surgical pain and pain at the end of life, such as cancer pain, has not been managed well. Therefore, these standards should have a significant impact on pain management for patients."

The AACPI and the nearly 50 State Cancer Pain Initiatives headed by nurses, physicians, pharmacists, social workers, and researchers have long been advocates for better pain control in the nation's health care system. These organizations say the new standards are a milestone in efforts to overcome barriers to effective pain relief.

Today's move will not affect all hospitals, nursing homes and other facilities — only those accredited by the JCAHO. The JCAHO accredits 80% of the nation's hospitals, accounting for 98% of the nation's hospital beds.

"Undertreating pain has been and still is bad medicine, and is often based on unfounded fear, ignorance, or miscommunication by health care professionals and patients," Dahl said. "Hopefully, the new standards will begin to change this." ▼

# Hospitals urged to adopt new end-of-life approach

Physicians can involve additional people in the care of terminally ill patients to ensure that their quality of life doesn't deteriorate in their final days, according to a study by Mayo Clinic researchers.

The study authors note that physicians as a group may prolong end-of-life suffering with aggressive approaches to "cure" the patients' underlying disease rather than acknowledging that the time has come to provide the patient with palliative care services.

However, strategies can be taken to reduce the suffering of a patient by orchestrating a multidimensional approach to helping ensure the quality of life at the end.

The special article, done for the Mayo Clinic Cancer Center Quality of Life Working Group, appears in *Mayo Clinic Proceedings*.

Before the 1900s, most Americans died at home surrounded by their loved ones. Currently, as many as 60% will die in hospitals, and up to an additional 25% will die in health care-related facilities such as nursing homes. Physicians have had an ever-expanding role in the manner in which people die, with so many Americans dying in hospitals and other health care facilities.

"With modern medicine emphasizing genetic manipulations, high technology, and cure at all costs, we often neglect what was once the most sacred aspect of being a physician: alleviating suffering," the authors write. "Therefore, we contend that the approach to a person dying in the hospital must change from simply postponing death to focusing medical interventions on maintaining quality of life to the end."

The authors defined the term "quality of life" as the physical, psychological, social, and spiritual domains of health that are influenced by a person's experiences, beliefs, expectations, and perceptions.

The Mayo Clinic authors conclude their article: "We believe that the principles that have been so successful in improving the quality of life for

hospice patients must be adopted in hospitals and related facilities such as nursing homes so that suffering can be relieved where the vast majority of Americans continue to die."

**Source:** Rummans TA, et al. Maintaining quality of life at the end of life. *Mayo Clinic Proc* 2000; 75:1305-1310. ▼

## Feds release \$125M for caregiver services

The federal Administration on Aging released \$125 million to states in January for programs supporting caregivers of elderly or disabled family members.

The federal money is set aside for programs supporting caregivers of older adults who have dementia or are significantly disabled. Relatives or guardians 60 or older who care for a disabled child also will benefit, recognizing, for example, the needs of older adults caring for adult children who are mentally disabled.

Among the states receiving funds are Oregon and Washington. Oregon will receive \$1.4 million and Washington will receive \$2.1 million as part of the National Family Caregiver Support Program under the newly reauthorized Older Americans Act.

"With the aging of our community, there aren't going to be enough family resources to take care of the elders and the children in a family," said **Mary Lou Ritter**, chairwoman of the Oregon Association of Area Agencies on Aging and Disability. "The funding is just the beginning of recognizing the impact on families of caring for a family member."

The money will go to the aging services agencies in each state. Clackamas County Social Services, for example, plans to spend its estimated \$132,000 on expanding respite services, giving more people a temporary break from caregiving duties, said **John Mullin**, agency director.

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■ Taming the documentation monster

Washington County's estimated \$100,000 will go to caregiver support groups, counseling, training, and connecting caregivers with social services.

"This is welcome funding for us to really be able to get in and do some good things for families," said Ritter, who is also director of the Washington County Department of Aging and Veterans Services. ■



## Pressure ulcers found in 9% of new home patients

A national chain of home care agencies found through a quality assurance report that one in 11 new home care patients enters the system with pressure ulcers. The report, published in the September issue of the *Journal of the American Geriatrics Society*, raises concerns about the quality of routine skin care measures for older adults in hospitals and nursing homes and points out the need for better wound care.

More than 3,000 home care patients from 14 states were examined as part of the study, 65% of whom had been discharged from a hospital or nursing home. About 9% already had pressure ulcers at the time of their first home care visit. Of those, roughly a third had two or more pressure ulcers, while three-fourths had advanced-stage ulcers.

The report also revealed that patients who began home care after being released from a nursing home or hospital were more likely to have pressure ulcers than other patients. Fifty-four percent of those with pressure ulcers received pressure-reducing mattresses or other devices on admission to the facility, and only 18% of those at risk received pressure reduction. Other risk factors for pressure ulcers included functional impairment, incontinence, and previous ulcers.

Most ulcers were being managed by wound care products, including dry or wet-to-dry gauze dressings. The researchers recommended educational

and quality improvement efforts to ensure that home care providers have the knowledge and skill to assess and manage these potentially dangerous wounds. ▼

## E-health groups have a quorum

Three Internet health organizations announced in October that they were forming a coordinating committee to collaborate on ethical conduct codes. The committee has a goal of ensuring a system of e-health codes that is understandable to the public and that uses a common terminology. The organizations involved in this committee are:

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### Editorial Questions

For questions or comments, call Lee Reinauer at (404) 262-5460.

- Hi-Ethics (Health Internet Ethics), a coalition of 20 of the most widely used U.S.-based consumer health Internet sites and information providers;
- The Health on the Net Foundation, a not-for-profit portal for medical and health-related information based in Geneva, Switzerland;
- The Internet Healthcare Coalition's e-Health Ethics Initiative. The Internet Healthcare Coalition is a Washington, DC-based nonprofit organization. Its initiative aims to provide a forum for the development of a universal set of ethical principles for health-related Web sites.

The first step of the collaboration will be the development of a common glossary of definitions and terms for verification and compliance efforts. E-health consumers should be able to easily compare security and privacy statements using universal descriptions. The common terminology will be used by the three organizations when communicating future developments. The groups hope their efforts may set domestic standards and may eventually lead to cooperation on an international level. ▼

## Michigan physician to pay \$2 million to government

A Michigan osteopathic physician agreed to pay the government \$2 million to settle allegations that he and a corporation he controlled overcharged the Medicare and Medicaid programs, the Justice Department announced on Dec. 27. The settlement resolves various allegations under the False Claims Act against Donald Dreyfuss, DO, in connection with services provided from 1992 to 1996 to nursing home and hospice patients in the Detroit area.

The settlement was announced by Assistant Attorney General **David Ogden** of the Justice Department's Civil Division and **Saul Green**, U.S. Attorney for the Eastern District of Michigan. Dreyfuss billed Medicare and Medicaid for provision of physician services to nursing home patients. The Justice Department alleges that the services were not provided or were not medically necessary, or the complexity of the services was exaggerated. It was also alleged that in connection with a hospice, Dreyfuss certified that patients were eligible for Medicare or Medicaid services when they were not. ▼

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## Underwear may help prevent hip fractures

A two-year independent study has found that frail seniors who wore HipSavers hip protector underwear were considerably less likely to experience a hip fracture than their less frail counterparts who didn't wear the undergarment.

The study, reported in a recent issue of *Advances for Occupational Therapy Practitioners*, examined a high-risk group from the Elder Service Plan of the East Boston Neighborhood Health Center. Of those who wore HipSavers, none experienced a hip fracture, compared to a 4.3% hip fracture rate in a group at less risk that did not wear the undergarment, even though the frail group had a historic rate of twice as many previous hip fractures and experienced five times the frequency of falls as did the lower risk group.

HipSavers are U.S. Food and Drug Administration-approved underwear incorporating a soft, thin pad over each hip bone to absorb and dissipate the impact of a fall. For more information about HipSavers, visit [www.hipsaver.com](http://www.hipsaver.com). ■