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Hospices reaching out to the community must be willing to pay

Outreach promotes understanding of death and dying issues

Certified hospices must provide bereavement support to the families of their deceased patients. What about those who ask for help in coping with losses otherwise unconnected with hospice care? Community grief services offered by American hospices range from individual counseling and support groups to school crisis intervention, bereavement camps for kids, counseling for the families of victims of violent crimes, and a variety of public education forums depending on local needs and the presence of other services in the community.

Some hospices charge on a sliding scale for community counseling or other grief services. Others seek mental health coverage from insurers or special funding. In most cases, community grief outreach is unlikely to pay for itself in terms of direct income. Instead, hospices must subsidize these services as part of their mission and their responsibility to transform the culture's understanding of death and dying issues, as well as using the opportunity to raise the public's awareness

The cost of understanding

For many hospices, the fiscal belt-tightening brought on by regulatory scrutiny and the plummeting length of stay has severely curtailed their ability to offer "extras" such as community grief and bereavement services. Yet for others the most obvious way to increase their community's understanding of and comfort level with hospice care is by reaching out to the broader community with services aimed at addressing the spectrum of issues related to grief, loss, and bereavement. These hospices may not be able to prove that community grief outreach will pay for itself down the road through increased, more timely utilization of hospice care. On the other hand, they point out, how else will hospice ever change the culture's openness to death and dying issues? ■

and comfort level with what hospice provides.

Judy Davis, LCSW, BCD, director of volunteer and bereavement services for San Diego Hospice, says her agency provides such services in large part because the community asks for it. "As a community-based nonprofit organization, we have a moral and ethical imperative to take what we've learned and pass it back to our community," she explains.

A value-added service

San Diego Hospice consults with school teachers, counselors, and nurses on how to work with children's grief and is frequently called in to educate managers about grief and loss issues in the workplace, Davis says. Its grief support groups are open to the public and are usually divided equally between the families of hospice patients and individuals not connected with the hospice. Davis' department gets about 200 requests for grief assistance every month, some of which receive immediate telephone crisis counseling.

The hospice doesn't charge for these services, and it tries to use volunteers for the low-risk, routine follow-up calls, leaving counseling to the paid staff.

"We're not interested in doing fee-for-service at all. It's a decision we made to make the service available to the community. Our hope is that a value-added service like bereavement support eventually might find an endowment," Davis says.

"The payback for hospice is that if we, as a society, are going to re-incorporate death into life, then hospice needs to be offering these learning opportunities to people who request them. The things we've learned from our patients and families are life skills that have application across the life spectrum. That automatically increases the awareness of quality-of-life issues at the end of life. It's a long-term investment, but if we don't start making that investment, we'll never get there," Davis says.

She offers an example of the hospice's twice-a-year presentations on issues of grief, loss, and dying in local high schools, which include a brief explanation of hospice care. One young participant told his family about hospice when his grandmother became terminally ill. "Is that why we do it? No. But where else would he have learned about hospice, and how else would they have heard about it?"

Judith Skretny, MA, director of the Life

Transitions Center affiliated with Hospice Buffalo, NY, and the Center for Hospice and Palliative Care in Cheektowaga, NY, says that hospice already enjoys a good reputation in her community.

"Community grief outreach does a great deal to support our hospice," she says. "It shows people that hospice is not so limited; it really is committed to the end of life and the idea of supporting people coping with serious illness and loss beyond the six-months-or-less requirement of the Medicare hospice benefit," she explains. "Every time we go out and do a grief program, we talk about hospice. It's a natural marketing tool, and an opportunity to correct misconceptions. I can't quantify the result, but I hope it helps people to find the idea of hospice more palatable," Skretny says.

'We are mission-driven'

The Life Transitions Center, which was as an independent center for grief counseling prior to its affiliation with Hospice Buffalo in 1992, currently has a budget of about \$750,000 and a staff of 17, Skretny says. It provides bereavement support for 2,000 families of the hospice's patients each year, as well as all of the organization's community grief counseling, education, and support. The center reaches out to the community in areas such as grief training for staff at local schools, a monthly bereavement ministry training for clergy and volunteers, and about 200 public education presentations on grief in a variety of settings. "We are *the* agency called in to respond in a crisis, because hospice is recognized as the expert on death," Skretny says.

Currently, the center offers 22 grief support groups for different target populations, such as men, suicide bereavement, younger widowed persons, and adults who have recently experienced the death of a parent. The hospice uses a sliding fee-for-service scale for both counseling and support groups, and is increasingly able to access insurance coverage for counseling, Skretny says. "We ask for donations for any crisis intervention or response. We have support from the United Way and we're always applying for specialized grants, along with the transfer of direct costs from its affiliated hospice for services provided to hospice patients' families. But it is a struggle. This agency will never be in the black, and we know that. Part of why we do it is because we are mission-driven. We have a commitment to this

community that we will serve everyone, regardless of ability to pay," she explains.

Responding on a smaller scale

Some smaller hospices, lacking the resource base of the San Diego or Buffalo hospices, have also sought ways to provide community grief outreach. In some cases, that means finding partners in the community, such as religious congregations with active volunteer ministries for collaborative ventures. In other cases, the hospice assesses the current availability of grief support in the community in order to identify an area of significant unmet need.

Blue Water Hospice, a program of the Visiting Nurse Association of Port Huron, MI, began its outreach with a desire of its board of directors to reinvest memorial donations in the community, says **Brenda Clark**, hospice administrator. "We did an informal community needs assessment and found that several other organizations were providing grief support for adults and for younger school children. The gap seemed to be teens, so we started with the schools, offering a Teen Grief and Loss Class." Blue Water Hospice now offers eight-week sessions to teens through the schools in the fall and spring. The hospice also offers teens education through school health classes. Meanwhile, the hospice is expanding to the preschool population with a program called "What color is your hurt?"

Boulder, CO, enjoys a community resource that **Kim Mooney**, BA, coordinator of community education and bereavement for Boulder County Hospice, jokingly refers to her program as "an infestation of therapists." The hospice has recruited 30 local mental health professionals who were willing to take the hospice's volunteer training and run grief support groups on a volunteer basis.

With this volunteer cadre, the hospice is able to offer a range of group settings, from structured and time-limited, to drop-in and ongoing, targeted at general or specific populations, Mooney says. A monthly three-session group, is designed for the newly bereaved, giving them a light combination of support and education to deal with the normal, distressing, symptoms and problems of a new loss.

"None of these groups is a therapy group. We spend time with our volunteers talking about the difference between therapy and support," Mooney explains. "We provide support and

education in a very profound way, but we don't label participants as pathological." The hospice refers those who need more assistance to its list of local grief-savvy therapists. Except for occasional crisis interventions, the hospice reserves individual grief counseling for hospice families.

"Our hospice grew out of the community, and out of a larger context," Mooney says. "What's required of us in a larger way is to be a resource to the community on death and dying. Unless people become more open to the idea of comfort and care at the end of life, we'll always be preaching to the choir. We want to have as much visibility as possible at times when we're not so scary to people. Our approach to death, dying and grief is to go through as many side doors as possible."

To achieve these goals, Mooney pursues constant and steady exposure through churches, senior centers, libraries, and local media.

"I think it's easy to reject or devalue that which doesn't clearly show measurable results, but from what I've seen, these kinds of personal conversations are the primary way people become open to the hospice approach. We're pursuing a conversation with our community, and that broadens the audience willing to look at us. I can't prove the value, but I see community grief as hospice's advance party." ■

NY hospices draft new AIDS standards

Epidemic is not over, insiders warn

New standards of hospice and supportive care for persons with advanced HIV may bring greater clarity to hospice's role in the epidemic. Developed by the New York City Hospice and Supportive Care AIDS Initiative, the draft standards were presented to other hospices at a conference of the New York State Hospice Association in October. The authors would like to see the standards published and distributed to hospices nationwide.

The nine-member AIDS Initiative, administered by the San Francisco-based Tides Center, was created three years ago at a meeting of the Downstate Hospice Alliance in New York City when area hospice directors compared statistics on hospice utilization for AIDS patients, relates **John A. Chermack**, the project's director. At that

time 35% of those who died from AIDS nationally were served in hospice; but the rate varied from a high of 68% in San Francisco to a dismal 2.7% in New York City.

The new standards are based on the National Hospice Organization's *Standards of a Hospice Program of Care*, but were adapted with the aim of removing barriers, including the *perception* of barriers, to hospice and supportive care for people with AIDS, Chermack says. Another major focus is on palliation, including the palliative use of anti-retroviral therapies in a hospice or supportive care context.

Anti-retrovirals, such as the new class of protease inhibitors, have sparked a revolution in HIV treatment in recent years, but many hospices believe they are both too expensive and too medically aggressive for hospice use.

"There are plenty of reasons why a patient might not want to give up these medications, and hospice has to be willing to consider what might otherwise be viewed as aggressive treatments because of their palliative uses," Chermack counters.

"Our standards of care commit programs to provide pharmaceuticals consistent with the current medical standard of practice which includes the availability of anti-retrovirals. The decision of whether to continue or discontinue anti-retrovirals is about whether the long-term benefit to the patient outweighs the side effects — not whether they're considered 'aggressive.'"

Chermack says that palliative benefits of anti-retrovirals include the potential to reduce the incidence or severity of:

- painful cellulitis;
- edema;
- dyspnea related to pneumonia;
- Kaposi's sarcoma;
- lymphoma;
- wasting syndrome;
- other opportunistic infections.

"There are also patients with AIDS-related dementia, for whom, if you discontinue protease inhibitors, they will experience increases in depression, delirium, anxiety, or psychosis. To dismiss the treatments out of hand will cause hospice to miss out on serving a lot of people who are in need."

Of course, barriers to hospice utilization may also come from the other direction, which is the unwillingness by many to consider hospice as an appropriate referral for patients with advanced AIDS.

"I've been to a hundred AIDS agencies in the

last 18 months. Many of them have such skewed ideas about hospice that they'd never consider making a referral: 'Hospice is a warehouse for the dying . . . or for when you've given up all hope of helping the patient,'" Chermack relates.

"I try to present hospice as the hope of improved quality of life or of dignity and independence when the disease is advanced. We don't want to take away hope of improvement, but we also are very realistic that we are dealing with a life-threatening illness," he explains.

"Part of the problem is the hospice requirement for a six-month life expectancy. Our guidelines focus instead on clinical criteria," says Chermack.

Physicians are unwilling to talk about six months or less, but they are willing to talk about lab results or other clinical criteria. "We want to emphasize that hospice is not giving up. It is providing additional, high-quality help at a time when that is needed."

The New York panel's recommendations indicate that hospice referral is appropriate for HIV patients who have CD-4 counts of less than 25; viral loads of more than 100,000 ml; and one or more life-threatening opportunistic infections or symptoms. However, they state that hospice admission should *not* be dependent on the presence of a do-not-resuscitate order or a live-in caregiver, nor on a requirement that the patient is imminently dying, bed-ridden, or homebound.

The challenge of anti-retrovirals

Paul A. Volberding, MD, of the University of California-San Francisco AIDS Program at San Francisco General Hospital, echoes Chermack's insistence on trying to make room for anti-viral therapies in hospice. Patients who fail the treatments or have high viral loads immune systems can still benefit from the treatments, Volberding tells *Hospice Management Advisor*.

He urges hospices to be flexible in their admission policies and drug coverage. He also contrasts patients just starting the anti-retrovirals — for whom the hospice might take a wait-and-see approach — with those on a third or fourth course of treatment. The latter may be unlikely to see dramatic turnarounds, but the treatment still could offer them enhanced quality of life.

Volberding also says that pain is an under-recognized and under-treated symptom in AIDS, which could provide an opening for hospices to share their pain management expertise

on a consulting basis.

The situation hospice faces with the changing AIDS epidemic is not unlike other AIDS service organizations. "We face it in our clinics. You need to re-look at your mission statement and who you are as a provider," Volberding says. "The dangerous thing is for an organization to dig its feet in the dirt. Not many people are dying of AIDS today, so you don't need as many beds. Do you shut them down, or do you say, 'Gee, we have these dedicated professionals, where's the real need?'" he relates. "Off the top of my head, maybe what's needed is respite care."

Despite recent gains, however, the epidemic will become worse again, Volberding predicts. "It's pretty naive to think we're not going to have progression from the disease. We're still in the honeymoon period with the therapies, and it's very predictable that things will get worse. Therefore, let's encourage programs to be flexible, to try to broaden themselves, with the thought in the back of your mind that you'll need some capacity in the future to re-include AIDS."

If hospice is willing to go down the anti-retroviral treatment path, he adds, it also needs to be knowledgeable about new drug therapies, their toxicities, drug interactions, and patient compliance issues. As new anti-retroviral drugs and combination therapies come on the market, these questions will become more complicated.

"In the world of AIDS, we need to keep learning. The web is a very useful tool, especially as a resource for agencies that see AIDS patients only sporadically." UCSF's HIV Insite is a good place to start, he says. (See resource list on p. 146.)

Finding new roles for hospice

"We, too, have seen a decrease in the number of AIDS patients in hospice," says **Claire Tehan**, MA, hospice vice president for Hospital Home Health Care Agency, Torrance, CA, an affiliate of Little Company of Mary Health Services. "We've spent time talking to our own agency's AIDS case management team. What we hear is, with the protease inhibitors, with all of the hope, people just don't want to hear about hospice. Patients are still dying, . . . either because the patient has clearly said no to hospice, or else the staff has some reticence. No referral is made to hospice. We're not content to let it be like that," Tehan says.

The hospice has obtained grant funding to explore alternatives. "Recognizing that to a very

significant extent, AIDS patients don't want to hear about hospice, and (are) recognizing we have some skills to offer in areas such as pain management. We'd like to find new ways to work with other HIV providers including our own agency's AIDS case management team. How can we go in and do pain consultation, using a teaching approach, and still make it clear that this is a hospice nurse who's an expert in pain? Then if the patient asks about hospice, it's a natural," Tehan relates.

Sense of urgency is waning

"We expect to find patients where the case managers feel they need some help, and possibly work with those providers on delivering bad news. That's a comment we have heard: bringing up a topic like hospice, even when it's very appropriate, is not easy," she says.

"I'm not sure we're always going to get HIV patients on hospice, but we need to try to work with HIV providers. If hospices don't do something, we won't ever be involved." Tehan adds that her hospice has rarely confronted the question of whether to cover anti-retrovirals. "Usually when they reach us, the anti-retrovirals have been stopped. I'm not aware of any situation where anybody is receiving hospice and still on the anti-retrovirals. If people are on them, even if they're doing miserably, they don't want to hear about hospice."

Kevin Mallinson, MSN, ACRN, a doctoral student at Johns Hopkins School of Nursing in Baltimore, says the real danger for both hospice and the nursing profession, "is that we have not seen the end of the AIDS epidemic; people have lost their sense of urgency about it. I'm afraid nurses will lose their expertise. When the treatments inevitably fail, I'm afraid we'll get back to where nurses — and hospices — don't know what they're doing," he explains.

"It has become almost politically incorrect to even talk about dying (from HIV). Well, call me a cynic, but I've been doing this work too long," he observes. "And the next population group in the evolution of the epidemic is the poorest of the poor. I don't think there will be as much motivation to learn again for them."

The grief of multiple losses is another area where hospice could play a key role, Mallinson says. "If all the deaths from AIDS stopped today, we'd still have to deal with the fact that so many in our community have died. If anything, people now have the time to sit back and say: 'Oh my

God, so many are gone!' In effect, it's a kind of post-traumatic stress response." ■

Resources

Kevin Mallinson was scheduled to present a pre-conference workshop on multiple loss issues at the National Hospice Organization's annual meeting in Dallas in November. For information, contact NHO at (703) 243-5900. Access UCSF's HIV Insite page at: <http://www.hivinsite.ucsf.edu>. For information on the New York City Hospice and Supportive Care AIDS Initiative, contact John Chermack at Madison Square Station, P.O. Box 9, New York, NY 10159. Telephone: (212) 420-2838. Fax: (212) 844-1802. E-mail: diazchermack@earthlink.net.

Hyde-Nickles bill defeated in Congress

Co-sponsor vows to try again

End-of-life and pain management advocates are celebrating — at least this year — the defeat of a bill that would have harnessed the enforcement power of the U.S. Drug Enforcement Administration to investigate and punish physicians and pharmacists suspected of participating in legalized physician-assisted suicide. (See *Hospice Management Advisor*, October 1998, pp. 121-122.)

On Oct. 14, Senate sponsor Don Nickles (R-OK) abandoned his effort to attach the Lethal Drug Abuse Prevention Act to the omnibus spending bill, which was approved by Congress the following week. Sen. Ron Wyden (D-OR) had announced on the floor his intention to filibuster the entire spending bill, if necessary, to prevent a back-door enactment of Nickles' bill.

House sponsor Rep. Henry Hyde (R-IL) previously had withdrawn the House version of the bill before it could come up for a floor vote. Nickles vowed to "pursue the matter next year," while opponents of the bill, including the National Hospice Organization (NHO) in Arlington, VA, and the American Medical Association in Chicago, pledged to seek alternative measures that better address the real needs and suffering of dying patients.

Right-to-life advocates had pushed the Hyde-Nickles bill as a litmus test for the conservative agenda and a way to overturn the twice passed *Oregon Measure 16*, which legalizes physician-assisted suicide. End-of-life and pain professionals, including many long opposed to assisted suicide; argued that the bill would have an unintended chilling effect on the prescribing of controlled substances for legitimate pain management, mainly because of doctors' well established fears of government scrutiny.

A coalition of 52 health care organizations, led by NHO, rallied the end-of-life community's opposition to the bill.

"I was heartened by the response by the hospice community in educating the members of Congress on this issue," says **John Giglio**, NHO's director of public policy and general counsel. "This helped elevate the debate on the underlying causes of assisted suicide, including the undertreatment of pain and the inability of many Americans to access appropriate end-of-life care. As a result, the hospice community has a tremendous opportunity to advance the dialogue with Congress on how to improve care of the dying," Giglio explains.

NHO is internally examining its next steps and hopes to work with other end-of-life groups to define legislative proposals. "If they have bipartisan support, there's a good chance Congress will consider them," he adds.

Joanne Lynn, MD, founder of Washington, DC-based Americans for Better Care of the Dying and another leader in the fight against Hyde-Nickles, urges hospice providers to "let us and NHO have their input on what kind of Congressional action they would like to see to improve end-of-life care. A lot of people on the Hill are interested in what they could do for the plight of dying patients, such as research studies or demonstration projects," Lynn says, although creation of new end-of-life medical benefits is less likely in the short run. "At least we've got to have some goals in mind."

In the wake of Hyde-Nickles defeat, some hospice leaders have wondered whether the vehemence with which the end-of-life movement pushed suggests the danger of partnering with that movement. One of the concerned hospice leaders is **Ira Byock**, MD, past president of the Reston, VA-based American Association of Hospice and Palliative Medicine and author of *Dying Well: The Prospect for Growth at the End of Life*, (published in 1997 by Riverhead Books, New York).

In a Sept. 30 editorial in the Portland *Oregonian* newspaper, Byock accused Hyde-Nickles boosters of trying to incite a new civil war similar to the abortion debate by escalating the assisted suicide debate “to a dangerous new level of conflict, while doing nothing to alleviate the suffering of dying patients. At a time when consensus building and constructive legislation is urgently needed — and would likely succeed — the bill’s backers have chosen instead to wag a moral finger at America,” he writes.

In a subsequent e-mail interview with *Hospice Management Advisor*, Byock labels the Hyde-Nickles effort “disgraceful” and adds, “we have learned that a small but powerful faction within the right-to-live movement is really more interested in moralizing than in alleviating suffering.”

If right-to-lifers were truly interested in relieving suffering and reducing patient demand for assisted suicide, they would “use the power of the congregations and parishes to declare a social right to die in comfort in a clean, dry bed. Instead, some right-to-life zealots seem willing to work with those of us in the caring community only to the extent that it advances their own, self-righteous political agenda.”

Strange bedfellows

Lynn, who was a target of attack by Hyde-Nickles advocates, says that “the things that separate us are still pretty small. Just like politics makes strange bedfellows, sometimes it makes strange opponents.” The battle over the Hyde-Nickles bill, she suggests, “was just an honest difference of opinion over whether something would work or whether it was important to do for symbolic reasons.”

NHO’s Giglio adds that advocates for the Hyde-Nickles bill “were not people who normally work on health issues. They literally didn’t understand or believe our objections. But I don’t think it reflects a larger trend of whether or not we should be working with right-to-lifers,” he observes. “I will bet that by this time next year, Congress will be considering a bill that the health community will be able to support.”

According to the Oct. 20, 1998, *Hospice News Network* electronic newsletter, Oklahoma State Hospice Association (OSHA) president **Steven Edwards** says he hopes “we can work together with Senator Nickles next year to accomplish common goals that also won’t hurt cancer patients and the terminally ill in hospice.”

Meanwhile an attempt to shift the assisted suicide debate to Michigan with a proposal called Proposal B failed in the Nov. 3 election. Placed on the ballot by a group called Merian’s Friends, the initiative was defeated nearly 3-1, but neither side says the issue is over.

The group is named for **Merian Frederick**, a Michigan amyotrophic lateral sclerosis (ALS) patient who committed suicide in 1993 with the assistance of **Jack Kevorkian**.

Many in Merian’s Friends are interested in bringing the issue back, perhaps in another four years, says **Bob Moreillion**, former campaign manager for the group.

The proposal resembles *Oregon Measure 16*, the first state law to legalize assisted suicide, and includes such safeguards as psychiatric determination, seven-day waiting period, and certification from two physicians that the person has less than six months to live before a patient could receive assisted suicide. (See related story on p. 148.)

Merian’s Friends gathered 250,000 signatures to get the proposal on the ballot, but had few resources left to purchase political advertising. Opponents spent between \$5 million and \$6 million on television ads to defeat *Proposal B*.

Ironically, Kevorkian, who claims to have helped more than 120 suffering patients end their lives, urged voters to defeat *Proposal B* because of its “stifling bureaucratic red tape.”

Kevorkian’s flamboyant attorney, **Geoffrey Fieger**, was the Democratic nominee for Governor of Michigan on this year’s ballot. He lost to incumbent John Engler, a staunch opponent of assisted suicide. Earlier this year Engler signed a new law, effective Aug. 1, outlawing assisted suicide and targeting Kevorkian’s activities.

Background on the story of Merian Frederick is contained in an article by her daughter **Carol Poenish** of Northville, MI, in the Oct. 1 *New England Journal of Medicine*. Frederick received hospice care during her final months of life, but the hospice did not know that she was also receiving visits from Kevorkian, Poenish states.

“It had to be done in secret — in a back alley. I realized after Mom’s death that many of the hardest aspects would have been eliminated if the choice she made had been legal. We wouldn’t have had to be so secretive; we might have had help in coming together sooner as a family, and we wouldn’t have had to go to Jack Kevorkian.”

Against this backdrop, a number of health associations such as the Michigan Health and

California gives dying patients pain relief

Calif. Gov. Pete Wilson has signed a new law, *A.B. 2693*, exempting terminally ill patients from the state's triplicate prescribing system for Schedule II controlled substances such as opioids for pain relief. The law, which takes effect Jan. 1, was sponsored by the California State Hospice Association (CSHA) in Sacramento and hailed as an important step in ongoing efforts to improve the under-treatment of pain. However, pain advocates are now challenged to get the word out about this new law to the state's medical community, CSHA reports.

Triplicates are state-issued serially numbered prescription forms to licensed physicians. One copy of each prescription is sent to the state Department of Justice in Sacramento. Although the intent of triplicates is to discourage inappropriate prescribing and diversion of controlled substances, they also have the effect of discouraging the legitimate use of narcotics for treating pain from serious illnesses such as cancer. Surveys have repeatedly shown that many physicians avoid prescribing triplicate-controlled drugs, often substituting less effective, non-triplicate drugs, because of their concerns about regulatory scrutiny.

Terminal illness in the California law is defined in terms of suffering from an incurable, irreversible illness that, in the reasonable judgment of the prescribing physician, will bring about the patient's death within one year, if the illness takes its normal course.

In a related development, New Jersey's prescribing law was recently changed to permit doctors to call in orders for an emergency supply of pain medications for terminally ill patients, to prevent them from waiting for pain relief. ■

Hospitals Association, the Michigan Hospice Organization, and the Michigan State Medical Society, all based in Lansing, have joined with the state's Department of Community Health in East Lansing in a program called the Circle of Light.

The first step for this group, which advocates

palliative or comfort care as a positive alternative for the critically ill, is to educate health professionals about new developments in palliative medicine. The project is also distributing state-wide ads with information about advance planning, a toll-free number for the Michigan Circle of Life Information Center, material on hospice and related issues, and a CD-ROM with patient-oriented information on cancer pain management.

In a related development, a new survey published in the Oct. 1 *New England Journal of Medicine* indicates that slightly more than half of patients with Frederick's disease, ALS, agreed with the statement: "Under some circumstances I would consider taking a prescription for a medicine whose sole purpose was to end my life." In fact, 44% said they would request such a prescription from their doctor if it were legal.

Reference

1. Ganzini, L., Johnson, W.S., et al., Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *New England Journal of Medicine* 1998; 339(14): 967-73. ■

News From Home Care

Congress enacts modest IPS reform

Shortly before adjourning, the U.S. Congress approved a \$1.7 billion home health "compromise agreement" aimed at fixing problems for providers created by the home health Interim Payment System (IPS), enacted with the 1997 Balanced Budget Act (BBA). However, the solutions are modest at best, postponing for a few months the predicted crisis in home health care. The industry will be paying for its own relief with future reimbursement cuts.

Susan Schulmerich, RN, MS, MBA, executive director of Montefiore Medical Center Home Health Agency in Bronx, NY, expresses the frustration of many industry leaders over the final version of IPS reform. "To me, it is unconscionable what the legislative and executive branches of the government are doing to home care patients and

providers. The delays and posturing have kept the industry on tenterhooks for months," she asserts.

"At the eleventh hour, legislative language was still being crafted to ostensibly 'right the wrongs' of the Balanced Budget Act. The frustration and fear of so many in the home care community is that the 'fix' will be temporary at best. We [providers] envision 1999 as a replay of 1998, another year of time and money, both in dwindling supply and in trying to obtain meaningful reform of IPS and the BBA."

The final home health provisions in the spending bill include changes in IPS-mandated per-visit and per-beneficiary limits and a one-year delay in the 15% across-the-board home health reimbursement cut that had been slated for Oct. 1, 1999. There will be no change in per-beneficiary limits for "old" home health agencies. Old agencies are defined as those with cost reports filed for fiscal year 1994 above the national median per-beneficiary limit imposed by IPS. However, such agencies at or below the national median will have per-visit cost limits calculated at 66.6% plus 33.3% of the national median.

Fewer patient visits

For home health agencies opening between Oct. 1, 1994 and Oct. 1, 1998, payments are changed to 100% of the national median. Agencies opening after Oct. 1, 1998, will receive 75% of the national median minus 2%. Even though the per-visit cost limit has been increased from 105% of the median to 106%, the per-beneficiary limit remains the same as calculated in the BBA. That will mean fewer visits to patients, predicts Schulmerich.

This modest reform was all the industry could muster, despite the extensive pro-home care rhetoric delivered at a National Association for Home Care-sponsored National Save Home Care Day, held Sept. 10 on the steps of the Capitol. At the rally, members of Congress affirmed the need to reform IPS in order to save home care. Industry leaders say the actual reforms passed this year will stave off disaster only for a few months. An estimated 1,400 home health agencies have already closed their doors during the IPS crisis, and this number could reach 2,000.

Given the limited relief doled out this year, it appears clear that the home care industry must continue to press for reform with the new Congress, Schulmerich says. She intends to fight to

protect the future of "an industry that is being chaotically dismantled as each day passes," and she urges colleagues to press their members of Congress for meaningful reform.

"It helps everybody to a certain extent, and it didn't create a new group of losers," **Ann Howard**, executive director of the Silver Spring, MD-based American Federation of Home Health Agencies, says of IPS reform. "But we, the disaster victims, are paying for the disaster relief. The other thing is that this whole exercise was all about providers. It had nothing to do with beneficiaries," or with the government's seeming attempt to cut coverage for long-term, medically complex home care patients.

"The problems need to be addressed very quickly. Otherwise, providers will be closing right and left. They were hanging on by their fingernails, looking to Congress. Many will feel they can hang on no longer," Howard says. "The next step for the industry, I believe, is that we need to focus on rationality and fairness for new agencies and to restore access for patients — two extraordinarily difficult tasks. It would also help if we could get the industry unified." ■

News From the End of Life

RWJF funds 21 innovative end-of-life projects

The Princeton, NJ-based Robert Wood Johnson Foundation announced in late October the award of 21 grants under its Promoting Excellence in End-of-life Care program. The projects, chosen from a pool of 678 applicants, include two hospices as primary grantees and several other hospices participating in collaborative efforts. Most of the three-year grants average \$450,000, with a total of \$9.1 million awarded.

"These projects have fresh ideas on how to make the fundamental changes we need in the structure, organization, and priorities of the health care system in order to promote high-quality end-of-life care," says program director **Ira Byock**, MD. "Their work, we hope, will help make changes that are long-lasting and spread to other institutions. In the long run, we hope they

improve the quality of life for a great many dying patients and their families," he says.

"The array of grants responds to acknowledged barriers to excellence in end-of-life care within existing health systems and structures. The grants will fund innovative strategies in a variety of settings, with particular attention to special contexts of care such as inner cities, isolated rural areas, and even prisons."

The funded projects also target hard-to-serve populations of dying patients, including children, people with serious, long-standing mental illnesses, and renal dialysis patients.

"Many of the grants involve leading hospice programs in innovative approaches that integrate palliative care within mainstream health systems," Byock adds.

Do they thus suggest the future direction of hospice? "Promoting Excellence in End-of-Life Care was well-named," he responds. "We're not retreating from standards of care, but we're trying to be flexible in the methods for achieving these standards. The grantees will raise the bar for planners and policy makers in their efforts to improve quality and access to comprehensive palliative care." ■

End-of-life partnership inches forward

A proposed national end-of-life advocacy group called Partnership for Caring is still under development (*See Hospice Management Advisor, October 1998, p. 123.*) "We've come a distance. We're being thoughtful in our process. And I believe we need a clearer definition before too much (publicity) splashing goes on," observes **J. Donald Schumacher**, PsyD, CEO of the Center for Hospice and Palliative Care, Cheektowaga, NY, and one of the Partnership's planners. Other leaders are Ira Byock, MD, past

president of the Reston, VA-based American Association of Hospice and Palliative Medicine, and Karen Kaplan, executive director of Washington, DC-based Choice in Dying.

The group's aims include channeling public concerns about end-of-life care into public advocacy, public education, and major advocacy campaigns in various media about the right to quality care at the end of life. "Just as the National Hospice Organization is talking about public engagement, we'd like to identify a process for beginning to engage people in a national conversation" about end-of-life care, Schumacher says. However, it will be important to include perspectives and voices from beyond the provider community in order to achieve those goals. Next step is a strategic planning session planned for Dec. 1, probably in the Washington, DC, area, he adds, bringing together 15 to 20 industry leaders to work on the organization's goals and vision. ■



Conference explores dying in prison

The first national conference on death and dying in prisons and jails was sponsored by New York City-based Project on Death in America (PDIA) and the Center on Crime, Communities & Culture (CCCC), was held Nov. 16 and 17 in New York. Keynote speaker for the conference, "Caring for Prisoners, Families and Caregivers," was **Sister Helen Prejean**, CSJ., author of the book *Dead Man Walking*, which was later made into a motion picture.

COMING IN FUTURE MONTHS

■ Update on hospice compliance plan

■ Cultural diversity issues in hospice

■ Human resources issues: Compassionate downsizing

■ New currents in cancer treatment

■ Can hospices really measure outcomes?

According to conference organizers, the field of dying inmates is largely unstudied despite the growing number of inmates dying in U.S. prisons and jails, and higher rates of suicide and AIDS. Resources to care for dying inmates, and bereavement support for their grieving survivors, including fellow inmates, are negligible at best.

However, a few innovative hospice programs and other supportive services were created in some institutions while community hospices have attempted to spur such development in others.

Earlier this year, a prison hospice opened at the Louisiana State Penitentiary at Angola, the largest prison in the United States. The Angola prison and hospice program are featured in a new documentary film called *The Farm*, which was shown and discussed at the conference, and in an article in the September 1998 *PDIA Newsletter*.

Tough sentencing laws

Louisiana has some of the toughest sentencing laws in the country, the article states. "The courts hand out a disproportionate number of life sentences; the parole board rejects all but a few requests. As a result, an estimated 85% of Angola's 5,200 inmates will grow old and die there."

PDIA associate director **Mary Callaway** toured the prison last spring and said she was amazed to see elderly wheelchair-bound inmates among the prison population. "One of the five compounds or camps at Angola is just for the elderly population — the geriatric camp," she told the newsletter.

Objectives for the New York conference explored both the needs of inmates facing death and their caregivers; understanding how to advocate for, provide, and administer such care; and developing recommendations for policy change. Other sessions addressed epidemiology, legal issues, and how to deliver palliative care at the end of life.

For more information, visit PDIA's Web Site: www.soros.org/death/pdiacale.html or the CCCC web site: www.soros.org/crime/center-events.html. Information is also available through Bill Gibbs of Imedex, the conference secretariat, at (770) 751-7332. Another important resource, the National Prison Hospice Association, can be reached at P.O. Box 3769, Boulder, CO 80306-0941. Telephone: (303) 666-9638. Fax: (303) 665-9437. E-mail: npha-news@npha.org. ▼

Hospital bed rate decides where people die

By far, the number of hospital beds in a community is the strongest determinant in whether a terminally ill patient dies in the hospital or at home, according to a new study published in the October issue of the *Journal of the American Geriatrics Society*. Analysis of the wide geographic disparities in end-of-life care, based on data from SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), a multisite study funded by the Robert Wood Johnson Foundation of Princeton, NJ, and the *Dartmouth Atlas of Health Care*, produced at the Dartmouth Medical School in Hanover, NH, challenges current assumptions about the choices patients might make if they were armed with better information.

The study indicates that unless local health care resources and practice styles are adjusted to meet

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Editor: **Larry Beresford**, (415) 824-2069. Fax: (415) 648-0370.

E-mail: 103672.675@compuserve.com

Group Publisher: **Donald R. Johnston**, (404) 262-5439, (don.johnston@medec.com).

Managing Editor: **Park Morgan**, (404) 262-5460, (park.morgan@medec.com).

Production Editor: **Nancy McCreary**.

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Editorial Questions

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the needs of dying patients, their wishes likely will not prevail. Over 80% of SUPPORT patients said they would prefer to die at home, but 55% of them died in a hospital. Nationally, 39% of all deaths in 1992 and 1993 were in a hospital; but this rate varied from 22% in Portland, OR, and Ogden, UT, to 54% in Newark, NJ. Medicare data suggest that a decrease of just one hospital bed per thousand population decreases the in-hospital death rate by 3.8%, while increased spending on hospice also corresponds with a lower rate of in-hospital deaths. ▼

Hospice nurses move on multiple fronts

The Hospice and Palliative Nurses Association (HPNA), of Pittsburgh is moving forward on a number of fronts to advance the discipline's standing. These activities include combining with other national hospice nurses associations, creating a foundation to promote education and research, and launching a peer-reviewed journal called the *Journal of Hospice and Palliative Nursing*, whose premiere issue will be released at the next HPNA annual conference, Feb. 10-13, 1999, in Clearwater, FL.

The Academy of Hospice Nurses (AHN), a smaller group allied with the American Academy of Hospice and Palliative Medicine (AAHPM) of Reston, VA, voted this summer to dissolve its organization and combine membership with HPNA. Of its 162 members, 43 already belonged to HPNA, and the rest joined HPNA's total membership of over 3,000 nurses, effective Aug. 15.

"We're excited about this merger," says **Marty Ayers**, HPNA's executive director. "It makes a stronger organization for hospice nurses, with no splinter groups out there," not that AHN was pursuing a conflicting agenda, Ayers says. Another immediate result has been an increase in contact between the nurses group and AAHPM.

Meanwhile, HPNA's affiliated National Board for Certification of Hospice Nurses (NBCHN) completed a national role delineation study of the critical professional tasks performed by hospice and palliative care nurses. Based on the results of that study, NBCHN is changing its name to the National Board for Certification of Hospice and Palliative Nurses, and revising the professional

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credentialing it offers to incorporate both hospice and palliative care nursing. New certification examinations beginning next March will award the designation CHPN (certified hospice and palliative nurse). In other changes, certification will no longer require a BSN degree or two years of full-time professional experience. For information on the certification program, contact NBCHPN at 211 N. Whitfield St., Pittsburgh, PA 15206, (412) 361-2470. ▼

Congress boosts needlestick prevention

Another overlooked provision of this year's Omnibus spending bill is a provision calling for the dramatic reduction in accidental needlestick injuries to health care workers. (See *Hospice Management Advisor*, June 1998, pp. 75-77.) An amendment sponsored by Sen. Barbara Boxer (D-CA) urges federal worker safety agencies to require the use of safer needles in health facilities, as well as a more accurate reporting of accidents.

Although nothing in the law is mandatory, the Occupational Health and Safety Administration (OSHA) in Washington, DC, endorsed Boxer's needle safety amendment. ■