

# HOSPICE Management

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## Looking for a hospice advocate? Consider your state's attorney general

*100-page report outlines barriers to quality care and highlights AG's role*

**M**ore patients die in institutions than at home among family and friends. Too many patients die in pain, and not enough of them experience peace and comfort in their final days. An untold number of people put their final wishes in writing, only to have them ignored.

To those who seek to improve the quality of care at the end of life, these realities are tragedies, the weight of which is measured by suffering and prolonged grief. While the humanity of the situation is not lost on Oklahoma Attorney General **Drew Edmondson**, it is the pragmatism of a lawyer's mindset that leads him to look at the issue more practically.

Failure to control pain or to provide health care in accordance with a patient's wishes is a matter of consumer protection, according to Edmondson. He says he hopes the 49 other attorneys general in the United States will see matters the same way. To persuade them, Edmondson, the outgoing president of the National Association of Attorneys General (NAAG), released a 100-page report titled *Improving End of Life Care: The Role of the Attorney General*. The report cites the testimony of experts and outlines the barriers to good end-of-life care. It offers glimpses into the lives of those who have watched a loved one suffer needlessly and delineates a state attorney general's role in making sure the dying are protected.

"I saw [improving end-of-life care] as a consumer protection issue after hearing the statistics," Edmondson says. "More people would prefer to die at home, yet more people will die in hospitals and nursing homes, and without pain control, many will suffer," Edmondson says. "I also freely admit that I was influenced by my wife, who is a social worker."

Linda Edmondson, a social worker specializing in end-of-life care, and others helped gather research, anecdotes, and other data during the year-long process. What they came up with provided a snapshot of both the good and the bad of dying in America.

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Edmondson used his term as president of the NAAG to focus on the legal issues surrounding end-of-life care and what attorneys general can do to ensure state and federal policies meet the needs of patients and their families.

"When asked about their expectations for end-of-life care, most people share the same concerns," Edmondson says. "We want to be free from pain, we want to be at home with family and friends, and we want our health care wishes known and honored. Despite these expectations, many Americans die in pain, isolated in some type of care facility, while their family fights to have their advance health care directives honored. I wanted to explore what state attorneys general could do to help stop this trend."

The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, is an enthusiastic supporter of Edmondson's efforts. "Attorneys general are in a unique position to bring parties together," says **John Keyserling**,

vice president of public policy at NHPCO.

Keyserling and other hospice leaders hope Edmondson's report and his work as NAAG president will lead to better communication between state leaders and hospice leaders. From these improved communications, law enforcement, physicians, elder care facilities, and others can emerge with a common expectation of quality end-of-life care.

The most evident conflict among the parties to the issue is between law enforcement officers trying to stem the misuse of opioid drugs and physicians who prescribe these drugs to manage patient pain. Fear of legal action has prompted many physicians to cut back on prescribing opioids.

"When Asa Hutchinson [administrator of the federal Drug Enforcement Agency] tells me that it is not the agency's intention to target physicians who are managing patients' pain, I believe him," says Edmondson. "Now, that needs to be told to the doctors and the local and state law enforcement."

Edmondson's report is designed to serve as a resource for attorneys general as they work to improve care at the end of life in their own states. The report contains information gathered during Edmondson's year-long tenure and details of what attorneys general are doing state by state to improve and promote end-of-life care.

"This is one of the issues that has to be on their radar screens," Edmondson says of his colleagues.

### **Three conferences sought testimony**

Edmondson's initiative revolved around a series of three listening conferences designed to discuss issues ranging from pain management to medical standards and education. These conferences focused on three end-of-life care issues: pain management, advance care planning, and professional competence. Modeled after congressional hearings, Edmondson and his colleagues listened to testimony and asked questions of experts and consumers.

The first panel, "Will My Pain Be Managed?," addressed the legal barriers to effective pain management. The second, "Will My Wishes Be Known and Honored?," examined the legal barriers to effective communication and implementation of consumers' expectations for end-of-life care. The third panel, "Will I Receive Competent Care?," considered the impact of state agencies on education and regulation of health care professionals in the effective provision of end-of-life care.

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#### **Editorial Questions**

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

"I did not want this initiative to be just legal theory," Edmondson said. "This is real life for real people. The physical pain and emotional distress are real. The response from attorneys general has been impressive, and I believe we have taken significant steps in the right direction."

Some state legislatures and licensing boards are trying to encourage better pain management and address physician fears about being targeted for violating regulations governing prescription of narcotics. But there still is a "significant gap between policy and practice," he concluded.

Edmondson's research revealed what end-of-life care advocates have been saying for years: Physicians, nurses, and other providers do not have enough training to adequately care for the dying.

State leaders who want to improve end-of-life care should do the following:

- Make aging issues a higher priority and support initiatives that improve conditions for the aged.
- Help encourage policies that improve consumer knowledge of end-of-life options, such as advance-care planning, and that encourage their use.
- Set state targets for training providers in palliative care, and find funding for this training.
- Require hospitals and nursing homes to establish palliative care services.
- Rewrite laws to encourage greater flexibility in the care of dying patients.

Leaders also can support major statewide pilot projects and coalitions that coordinate health care services with the aim of improving end-of-life care.

Attorneys general can pursue many steps. For instance, they can:

- Issue opinion or advice letters clarifying end-of-life issues and distribute them widely.
- Make available simple guides on advance-care planning.
- Send liaisons to hospitals, nursing homes, and other such settings to discuss and clarify end-of-life issues.
- Post relevant end-of-life information for consumers, attorneys, and clinicians on their Web sites.

Attorneys general can even push legal action

when appropriate. For example, cases can be pursued against a facility that knowingly disregards a dying person's advance directive and even against physicians who fail to provide adequate pain management.

Lawmakers and attorneys general working together can write new legislation that helps doctors better tend to dying patients.

"The attorney general ought to be seen as an ally of consumers who want their voices heard and of those caring for patients near the end of life," wrote Maryland Attorney General **J. Joseph Curran** and Maryland Assistant Attorney General **Jack Schwartz** in the report. "The visible engagement of the attorney general and his or her staff will itself help change the atmosphere for the better," they wrote.

Edmondson says an attorney general can take the following steps to promote high-quality end-of-life care:

- Render opinions that affect the behavior of law enforcement agencies, local judiciaries, and health care providers.
- Seek to bring parties together and promote a dialogue.
- Take on cases where consumers were harmed by poor care.

Curran and Schwartz echoed those very sentiments in the report. They listed the following as AGs' responsibilities with regard to end-of-life care:

• **Interpreting and explaining current law.**

At best, the law provides a clear-cut explanation of how people are supposed to act. Often, however, laws can seem to be at odds with patient rights. An attorney general can serve as an authoritative interpreter of the relevant law. For example, an AG can issue an opinion or advice letter about a clinical issue that has been brought to the attention of the AG's office and can make his or her opinion widely known within the state to affect the actions of other providers in similar situations.

AGs also can help consumers understand how to do advance care planning by distributing plain-language literature that explains the process and includes specific information about designating a proxy or declaring one's treatment preferences, the Maryland attorneys wrote.

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- **Giving advice to state agencies.**

AGs have a responsibility to not only give technically sound legal advice to policy-making agencies; they also have a responsibility to put both the law and its impact on those affected in a context that can be understood by agencies that must carry out policies based on the law.

“Good lawyers do more than give clients technically sound legal advice,” Curran and Schwartz wrote. A lawyer may refer not only to law but also to other considerations such as moral, economic, social, and political factors that may be relevant to the client’s situation.

They used the following example: The agency that licenses and inspects nursing homes can significantly affect the quality of end-of-life care for nursing home residents. The regulations that the agency enforces ought to be applied with sensitivity to the special circumstances of dying patients. For instance, the attorney general can advise that a regulation calling for certain minimal nutritional levels, which makes sense when applied to the nursing home population in general, need not be construed to mandate the use of feeding tubes in dying patients, for whom such intrusive efforts achieve no benefit.

- **Enforcing criminal law.**

An attorney general should promote the idea that legitimate law enforcement goals should be pursued without adversely affecting the provision of quality end-of-life care. This can be done through enforcement of criminal laws or by advising other law enforcement agencies.

For example, systems for monitoring narcotic prescriptions should be assessed to determine whether they are having an adverse impact on legitimate physicians by causing them to refrain from prescribing opioids out of fear of prosecution. **(See related article on p. 115.)**

According to Curran and Schwartz, the attorney general should convene pain management experts, police, prosecutors, and a medical examiner for a screening tracking system. The attorney general and palliative care experts could present a case that would prompt a homicide investigation, when there is, in fact, a legitimate use of narcotics.

“It is facile, and often incorrect, to suspect wrongdoing based solely on the level of morphine or similar drug in a patient’s bloodstream after death, and a high-profile investigation can have a destructively chilling effect on physicians generally,” they wrote. “An attorney general could ensure an expert review of the facts before matters are made public.”

- **Engaging in legislative advocacy.**

While attorneys general do not set the legislative agenda, they can serve as advocates for legislation that would improve end-of-life care. Their perceived expertise in the matter may also cause them to be sought after by lawmakers to help draft legislation. For example, if legislation is needed to ensure physicians’ orders for end-of-life care are honored in any care setting, attorneys general could help draft the appropriate legislation and advocate for it in the legislature.

Also, states would benefit from an ongoing advisory body led by the attorney general to monitor trends in end-of-life care and recommend changes in law and practice.

So where do hospices fit in? Hospices must be active partners in an attorney general’s initiatives to improve end-of-life care and the protection of terminally ill consumers, Edmondson says.

Attorneys general should convene stakeholders in the movement to improve end-of-life care, including hospitals, hospices, physicians, nurses, and law enforcement, he says. Aside from ironing out differences, these groups should hammer out a plan for educating their constituents and the public. ■

## Active AGs are making a big difference nationally

*AGs undertake EOL initiatives, education programs*

Although Oklahoma Attorney General **Drew Edmondson** focused his year-long presidency of the National Association of Attorneys General (NAAG) on improving end-of-life care and urging his colleagues to take a more active role in protecting terminally ill patients, several of his colleagues are at the forefront of changing state policies and affecting provider and consumer behavior.

In his 100-page report, *Improving End of Life Care: The Role of the Attorney General*, Edmondson and the NAAG praised several states for their efforts to educate the public, change provider behavior, advise state agencies and lawmakers, build coalitions, and prosecute those who abuse dying patients or ignore their wishes.

What follows is the report’s description of some of the states’ best practices:

## **ARIZONA**

The Arizona attorney general has focused on public awareness, education, and community programs promoting advance directives. After reviewing the law governing health and financial powers of attorney, the Arizona AG's office created care planning documents that are printed in booklet form. These booklets help consumers prepare durable health care power of attorney, a living will, a pre-hospital medical directive or do-not-resuscitate order, a durable mental health care power of attorney, and a durable general power of attorney.

Consumers can plan their own health and financial futures with these documents, which are presented in an easy-to-read format, including instructions on how to create legally valid forms.

In addition to creating and distributing these forms, the Arizona attorney general holds community outreach and education seminars. This year the AG's office has already held 16 seminars on life care planning, presented by the office's Elder Affairs Program. The presentations are made available on the attorney general's web site at [www.ag.state.az.us](http://www.ag.state.az.us), where consumers can download them.

## **CONNECTICUT**

Attorney General Richard Blumenthal has promoted the concept of Physician-Assisted Living (PAL) in Connecticut, a joint effort between his office, the Hospice Institute for Education Training and Research, and the Connecticut Bar Association.

PAL is an instrument designed to help medical professionals communicate with their patients about their needs. The PAL initiative allows individuals to express a preference for hospice care before the onslaught of pain and depression. It employs a document similar to the living will and power of attorney for health care instruments, called the Notice for Desire of Hospice Care.

Interviews conducted by the institute with hospice families during the last six years show that PAL has contributed to fewer days lost from school and work, fewer emergency room visits, and less depression associated with hospice care.

## **HAWAII**

The Kokua Mau (a Hawaiian phrase meaning "continuous care") project is a statewide campaign backed by a 260-member coalition of agencies, health care providers, and community groups. The project was born out of a 1998 Blue

Ribbon Panel on Living and Dying with Dignity, convened by Hawaii's governor. The panel concluded that Hawaiians lacked or were limited in the following:

- sufficient access to their own rich and varied spiritual and cultural resources;
- public and professional awareness about good end-of-life care;
- use of advance directives;
- use of hospice;
- adequate pain control.

The coalition was instrumental in the 2002 passage of a state law eliminating duplicate prescriptions for physicians when prescribing controlled substances for pain. This legislation was a collaborative effort between the Cancer Pain Initiative and Hawaii's Drug Enforcement Agency.

State officials also are trying to raise awareness about end-of-life issues. Speakers were provided with curriculum materials and handouts regarding planning ahead, talking about preferences with others, controlling pain, and acknowledging and respecting cultural differences. Presentations were made in a variety of settings, including long-term care facilities, caregiver conferences and meetings, senior centers, legal aid forums, regular meetings of retirees, clubs, military units, and businesses.

In a program coordinated by St. Francis International Center of Healthcare Ethics in Honolulu, health care workers were trained in pain management at 12 long-term care facilities and began tracking pain as a vital sign.

The Uniform Health Care Decisions Act combined into one statute the stipulations of the living will and durable power of attorney for health care; provided for surrogate decision-making in the case of the "friendless" patient; mandated safeguards for patients; and established penalties for noncompliant health care providers.

The Advance Health Care Directive Act of 1999 required the Department of Motor Vehicles and the State Civil Identification Branch to ask all applicants to indicate whether they had an advance directive. In March 2003, 26% of all those renewing licenses indicated they had an advance directive.

## **MAINE**

Maine laws give citizens the opportunity to express their wishes regarding the type of care they want to receive once they no longer have the capacity to make decisions. The laws are not limited to end-of-life care decisions and can include

pain management or other medical care decisions. A format for the health care directive is provided in the state statute. In the absence of a written health care directive, the Maine statute permits surrogates to carry out the wishes of the individual that were expressed while competent.

In 2002, representatives from the Office of the Attorney General, the Department of Human Services, and the Bureau of Elder and Adult Services began reviewing deaths and cases of serious bodily harm where abuse and neglect of elderly and vulnerable adults are suspected, including cases where providers may have failed to provide reasonable and appropriate end-of-life care. The review will serve as a catalyst for system changes aimed at improving response to victims and preventing similar outcomes in the future.

Assistant attorneys general assigned to the medical boards assist in reviewing complaints regarding the appropriateness of end-of-life care to ensure competent care is rendered. This is part of the office's policy of trying to make sure patients have access to appropriate, affordable medications.

The Maine attorney general has also been involved in litigation that would affect end-of-life care. The office's Healthcare Crimes Unit actively investigates providers of MaineCare, the state's Medicaid system, who abuse or neglect patients. The Healthcare Crimes Unit can initiate prosecutions when warranted. A recent case included an end-of-life care issue. At the conclusion of the investigation, a referral to the medical examiner's office and the licensing board was made.

## **MARYLAND**

In the area of pain and other symptom management, the Maryland Attorney General has worked to clarify legal issues. Health professionals and the public were notified that nursing homes have a regulatory obligation to provide medically appropriate pain management for terminally ill residents, and that Maryland's Assisted Suicide Act does not apply to medically appropriate measures to relieve pain and other symptoms. Physician educators were enlisted in the development of a web-based training program for medical residents, including a statement from the Attorney General's Office reassuring physicians that use of opioids for appropriate symptom relief will not result in prosecution.

The office also has helped draft legislation and has analyzed and defended current laws that protect the rights of individuals, including legislation that requires Medicaid applicants to give special attention to advance directives, do-not-resuscitate (DNR) laws regulating the practices of EMS workers, and laws exacting penalties for nursing homes that ignore DNR orders.

## **NEW MEXICO**

In October 2002, the New Mexico Health Policy Commission completed a report on end-of-life health care issues in the state. The report, which was requested by the state legislature, involved a myriad of professionals, including two attorneys from the New Mexico Office of the Attorney General.

The report included a study of pain management in the state that raised several critical areas of concern:

- the need for more education about pain and pain management for both patients and health professionals;
- limited knowledge about the etiology of pain;
- limited knowledge of the actual risks and benefits of opioids in the treatment of pain and effective pain management by health professionals;
- lack of attention given to pain management in the curricula of the professional schools;
- the fact that licensure requires no competency in pain management;
- fear among health care providers that they make themselves vulnerable to discipline or legal action when they prescribe opioids and other narcotics for pain;
- the need for the creation of a State Advisory Council on Pain Management, which would be responsible for instituting statewide education efforts for both providers and patients.

## **OHIO**

Building upon the office's Senior Protection Initiative in May 2003, Attorney General Jim Petro created the Child and Elder Protection Section of the Ohio attorney general's office in an effort to expand protections for Ohio's most vulnerable citizens.

The new section, composed of presently existing units from the Corrections Litigation, Crime Victims, and Consumer Protection sections of the attorney general's office, along with programs currently housed in the Ohio Bureau of Criminal Identification and Investigation, will assist local

prosecutors in investigating and trying elder abuse cases, as well as Internet and computer crimes against the elderly.

The office also participates in a program that matches volunteer lawyers from the office with low-income senior citizens or people facing end-of-life issues who are in need of legal services in the area of preparation of wills, durable powers of attorney for health care, and general powers of attorney.

## **OKLAHOMA**

Attorney General Drew Edmondson assigned an assistant attorney general to act as a liaison with the state coalition on end-of-life care for the past four years. This assistant has worked with the Oklahoma Association on Health Care Ethics and the Robert Wood Johnson Foundation-funded Alliance for Better Care of the Dying, in addition to making presentations to state agencies related to health care and to the public on end-of-life care.

As a result, the current governor and immediate past governor endorsed Palliative Care Week in Oklahoma and stood side by side with

Edmondson to inform Oklahomans of the importance of advance health care directives.

Recently, the office's Medicaid Fraud Control Unit prosecuted a nurse for felony caretaker abuse and misdemeanor verbal abuse by a caretaker. The nurse worked the evening shift at a nursing home. One of the patients complained about treatment from the nurse several times. The person holding power of attorney for the patient placed a video camera and monitor in the patient's room and advised the nursing home administrator of his action. The administrator, likewise, notified the staff of the camera recording events in the patient's room. Amazingly, the nurse continued to treat the patient in an abusive manner. In addition, an investigation revealed that the nurse had failed to administer pain medication on several occasions during her shifts.

The nurse waived a preliminary hearing and entered a guilty plea and received a five-year deferred sentence. A condition of her probation is to refrain from employment as a caretaker for the elderly. Her nursing license also was suspended. ■

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## **Pain-relief measures take root nationwide**

*Despite progress, much pain still poorly managed*

Attorneys general should play a role in advising state agencies and educating others about how laws and policies related to end-of-life care should be enforced, especially if they seem to be at odds with patient rights. The most salient example of this conflict has been the ongoing battle between end-of-life care advocates and law enforcement agencies.

Efforts to stem drug diversion, particularly for the drug OxyContin, have physicians fearing prosecution if they regularly prescribe opioids or if a terminally ill patient dies.

Oklahoma Attorney General **Drew Edmondson**, the outgoing president of the National Association of Attorneys General (NAAG), says his colleagues must use their position to educate physicians, prosecutors, medical boards, and others about the intention behind federal and state anti-drug laws.

"The AG should convene the parties and explain that the law is not intended to punish physicians who use these drugs appropriately,"

Edmondson says.

In the same year that Edmondson made improving end-of-life care a focus of his one-year term as NAAG president, there have been encouraging signs that honest physicians have little to fear, while those who fail to provide comfort through pain management drugs are at risk for criminal punishment or professional sanctions.

According to the *American Medical Association News* in June, three studies concerning medical boards, prosecution, and pain-treatment guidelines showed progress in differentiating criminal physicians from compliant ones. The studies were published in the Spring 2003 issue of the *Journal of Law, Medicine & Ethics*.

The first study was a survey of 38 medical boards, which found that boards were abandoning drug quantity as a marker of questionable practice and assessing instead whether a doctor properly evaluated a patient and followed the board's pain treatment guidelines.

A second study of county prosecutors in Oregon, Maryland, Washington, and Connecticut found the likelihood of investigation or prosecution for prescribing medications for pain management "extremely low."

A third study said more boards had adopted pain management guidelines but recommended

that they take further steps to train investigators about pain standards and circulate guidelines to physicians.

When the AMA last published its annual state-by-state review of pain policies, it found encouraging data. State regulators, according to the AMA, are taking unprecedented steps to help physicians provide relief to cancer patients and others suffering from chronic pain.

The AMA's pain policy expert, **Aaron M. Gilson**, PhD, said, however, that despite the availability of many pharmacologic and non-pharmacologic approaches to the treatment of pain, pain remains inadequately managed, due in part to concerns about addiction and legal sanctions.

The AMA's annual report in 2001 found a steady adoption of state pain policies that ease constraints surrounding the use of opioid analgesics for the treatment of pain. These policies were developed by medical regulators and can result in more pain patients receiving appropriate treatments, says Gilson, chief policy researcher and assistant director of the Pain & Policy Studies Group at the University of Wisconsin in Madison.

### ***State medical boards: Pain is undertreated***

In 1998, the Federation of State Medical Boards developed model guidelines that encourage the use of controlled substances for pain therapy and give physicians guidance in the use of controlled substances. The guidelines also recognize that pain is undertreated, partially due to physician concern regarding investigation by state regulatory agencies and medical boards.

"This is unprecedented policy development. Not only did it come from a national regulatory organization, but it also represents input from a multidisciplinary panel of experts from medicine and from medical regulation," Gilson says. The policy was disseminated to medical boards in each state.

The report found that state policies addressing the appropriate use of controlled substances for pain management increased from six in 1989 to more than 80 in 2001; some states have more than one policy. In addition, the report suggested that 22 states have developed policies addressing the use of controlled substances for pain that are based on the model guidelines. Twelve states adopted the policy in its entirety.

"Most states now have some type of policy relating to pain management," says Gilson.

Still, the AMA says some state policies, especially those not based on the model guidelines, contain language that has the potential to impede the use of opioid analgesics and restrict patient access to adequate pain management.

"Considering the increased collaboration between medical regulators, drug regulators, and the health care community, I am hopeful that these policies translate into more appropriate pain management for patients and lessened concerns about unwarranted discipline of physicians," Gilson adds.

2003 saw a number of other developments in pain management at the state level. In Florida, proposed prescription tracking legislation failed to pass in the final moments of the state's legislative session. Many complained that tracking systems would have a chilling effect on physician prescribing patterns. Rather than risk investigation and discipline as a result of one interpretation of prescribing habits tracked on a system, physicians may not prescribe opioids at all, critics say.

The bill would have created a program to track prescriptions for Schedule II, III, and IV medications, which include many pain and psychiatric drugs. Supporters say a tracking program would prevent prescription drug overdose deaths.

Purdue Pharma, the Connecticut-based manufacturer of OxyContin, pledged \$2 million toward financing a tracking program last year as part of an agreement with the Florida Attorney General's office to end an investigation into the company's marketing practices. This is the second year that Florida legislators have considered and declined to pass legislation on the program.

In Virginia, the state received \$180,000 from the U.S. Department of Justice to fund a prescription tracking program approved by the state legislature last year. The two-year pilot program will focus on counties in southwest Virginia, where prescription drug abuse has become a major problem in recent years.

The program will allow police to access a database containing information about prescriptions for Schedule II drugs, such as OxyContin, methadone, and Percocet.

Virginia Attorney General **Jerry Kilgore** favors the tracking system, saying the database will be useful in curbing abuse of the prescription pain medication OxyContin.

The database is expected to be operational by late summer or early fall, according to **Robert Nebiker** of the state's Department of Health

Professions, which will oversee the program's operation. It will be accessible only by law enforcement officers who have an active investigation into a patient or doctor. The law creating the pilot program makes unauthorized release of database information a misdemeanor.

U.S. Rep. **Frank R. Wolf** (R-VA) has asked the U.S. Department of Health and Human Services to restrict OxyContin prescriptions to patients with severe pain. Wolf has also requested that Health and Human Services Secretary Tommy G. Thompson take steps to warn the public about the dangers of OxyContin abuse. His letter to the agency cites a link between OxyContin and overdose deaths and robberies in his home state of Virginia and argues that "[t]he drug should not be marketed to treat moderate pain." Wolf chairs the House Appropriations subcommittee, which oversees the Commerce, Justice, and State departments and related agencies. ■

## Hospice Trends

### Can hospice houses be financially viable?

*Lack of third-party payers a stumbling block*

By **Larry Beresford**

What is the enduring appeal of "hospice house" residential facilities for America's hospice industry?

Recent traffic on end-of-life professional listservs, presentations at the National Hospice and Palliative Care Organization conference in September, and new projects under way in communities from coast to coast attest to hospice houses' continued attraction for hospices seeking ways to establish and operate houses of their own.

Freed from many of the code requirements and regulations of long-term care facilities or acute inpatient units, these hospice houses often create a much more comfortable, serene, homelike atmosphere for terminally ill hospice patients who cannot be managed in their own homes. Sometimes, the residence and its landscaped grounds just seem to say "home" to all who see

its panoramic vistas, outdoor patios, stained-glass windows, and antique furniture. Other amenities can include individualized food service for residents and their visitors and liberal pet and child visitation policies.

But with a few exceptions, the room-and-board costs of residential hospice care currently are not reimbursed by third-party payers. As a result, someone else needs to cover the operating expenses. That could be the patient or family paying a hefty daily room-and-board rate out of pocket; the larger community through a capital campaign, endowment fund, or other donations; or the hospice itself, subsidizing operations out of other income streams.

Residential hospice care has an important place in the end-of-life care continuum for patients who don't need the intensity of acute hospice general inpatient care and who don't want to be in a long-term care facility but who can't remain safely in their homes. Many live alone and can no longer manage on their own, or they don't have a home, or their family caregivers are worn out — or just in need of respite.

Proponents say these residences allow the hospice to serve a population of patients who otherwise would never even get referred because they lack family caregivers or a viable home environment. The residence also may be an outlet for actively dying, hospitalized patients who are too sick to go home.

Hospice houses make attractive fund-raising projects, in part because they assert a concrete, physical presence that home-based care does not. The hospice house, artfully designed and landscaped, can even be a visual symbol and embodiment of the hospice's philosophy and its presence in the community. Some facilities have child care, public meeting rooms, or other amenities that drive home the point.

Residents of hospice houses typically qualify for the routine home care reimbursement rate under the hospice benefit, which covers medications, equipment, nursing, and other professional hospice services just as if they were living in their own homes. Room-and-board expenses generally are not included in that rate and are billed privately at a separate daily rate subject to a means-tested sliding scale.

The use of volunteers to staff the facility may help keep costs down, but the hospice has quality and safety obligations and should not try to scrimp on the support and supervision needed by residents of its hospice house.

The capital campaign is just the tip of the iceberg in terms of the challenges of launching a successful hospice house project, notes **Mary Michal**, a health care attorney at law firm Reinhart Boerner Van Deuren in Madison, WI. Michal, who has considerable hospice experience, has developed a checklist of 11 tips for hospices considering a hospice house. Among other suggestions, she recommends that hospices make sure their donor base and their clinical infrastructure, including a medical director, are solidly in place and that they are maximizing operating efficiencies in their home-based programs before embarking on facility-based care.

**Jay Mahoney**, a hospice consultant with the Summit Business Group in Penfield, NY, says his firm usually does not recommend that client agencies pursue strictly residential-level hospice house projects, although many are interested in exploring them. Third-party reimbursement for residential hospice care from a few Medicaid demonstration projects or private health plans is sporadic at best, he explains. "So how does it get paid for? It gets paid privately" by the patients and their families, he says. "There are people who can afford to pay for residential care, and there are hospices that are making it on such payments."

On the other hand, Mahoney says, the hospice wouldn't want to limit access only to those able to pay the full charge. "By and large, if you are truly charging your actual operating costs, not that many people could afford it. My impression is that covering operating costs from operational revenues can be pretty difficult, although not impossible."

This reimbursement reality points most hospices toward fundraising as an alternative funding strategy. Fundraising for a residential facility can sometimes open new doors to sources that never donated to the hospice before. On the other hand, Mahoney says, if a hospice can raise enough money to open and operate a hospice house, that raises the question of whether that money might have been better spent on other patient needs.

Hospices also believe that a residence can close a significant gap in the end-of-life care continuum. It may give the agency greater visibility with referral sources and could generate positive impressions that could result in the referral of other patients. There is some anecdotal evidence to suggest such benefits, Mahoney says, while hospices might generate additional revenues from their physicians making daily rounds in the facility. There also may be economies of scale

and reduced travel costs from having patients concentrated in a single location.

However, Mahoney observes, the most viable option for funding residential hospice care appears to be incorporating residential hospice beds within a freestanding inpatient facility where at least half of the patients are maintained at a general inpatient level of care, providing a more predictable source of revenue. "That's what my clients have tended toward," he says.

Michal confirms this conventional wisdom that some proportion of general inpatient-level care is needed for a hospice house to break even. She also urges hospices planning residences to seek legal advice to make sure they fully understand the anti-kickback issues and the implications of providing free care in a hospice house without a carefully constructed sliding scale.

### ***Benefits of residential projects***

**Ruben Liebhaber** is a project development manager in Lexington, MA, who specializes in hospice residential and inpatient projects. He also is a volunteer at Tippet House, a hospice residence in Needham, MA. "I have witnessed first-hand how important an option residential care can be," he says. "There are many situations where family members can't supply the care or the home environment is just too erratic." Hospice houses make it possible for these patients to get the care they need while taking a burden off their families. In many cases, the only other alternative would be a nursing home.

Liebhaber tells his clients to expect room-and-board costs in a hospice house to run roughly \$120 per day, depending on a variety of factors including beds, occupancy rates, and actual operating expenses. He suggests that a target census of 14 to 16 beds, evenly split between residential and general inpatient levels of care in a facility properly designed to accommodate both, could break even — at least on paper.

While the majority of terminally ill hospice patients can be served at home, a program with a census of 100 or more may already have a critical mass of patients who could benefit from the residential alternative, depending on what the obligatory needs assessment reveals.

"I have visited 18 hospice residences, and they are, without exception, places where terminally ill patients would be well-served," Liebhaber notes. He points to increased openness to the concept of residential hospice care options among Medicaid

plans and private payers and the potential for competition among hospices to further push the trend.

"This will be market-driven. I expect that within five to 10 years there will be a shift in the viability of hospice houses and a groundswell of interest and support," he says.

An example of the lure of the hospice house concept is found in the work of Duluth, MN, physician **Joel Carter**, MD. Carter has a fellowship in end-of-life medicine from the Bush Foundation of Minnesota, which he is using to study the feasibility of developing a freestanding hospice house for the Duluth area. After visiting other hospice residences and surveying their operators, he has concluded that this project will require substantial community support, although not more than Duluth can afford.

When Carter asked managers at one of the sites he visited what they would do differently based on their experience, they answered that they would endow the building before opening for business.

Carter's business plan, still being developed, likely will recommend that an independent non-profit organization operate the facility in service of both of Duluth's competing health system hospices. He hopes to incorporate medical student training through the local medical college and to complete bricks-and-mortar work within three to five years.

"There are many ideas of what residential hospice means and the value our culture puts on home," Carter says to explain the origins for his project. Some people don't have homes to die in or can't cope, or else their family caregiving breaks down. A hospice house could serve their end-of-life needs while making death and dying more of a community event, he says.

"A couple of the hospice houses I visited were in beautiful wooded areas. Their directors told me a very curious thing. When a resident is dying, there are increased sightings of wild animals on the grounds."

*[Editor's note: For more information on hospice houses, contact project development manager Ruben*

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## Education programs create loyal, valuable employees

*Language classes, GED classes pay off*

Finding the secret to successful retention of home health aides is not easy, but HomeCare Options, a Paterson, NJ, agency with 350 aides with an average tenure of eight years, may be holding the key to the success other agencies want.

Because aides are most interested in learning skills that help them now in both their jobs and their personal lives, HomeCare Options took a close look at who made up their work force, says **Ken Wessel**, MSW, ACSW, LSW, executive director of the agency.

"The majority of our aides are Hispanic, many without a high school education and many for whom English is a second language," he says.

To help the aides gain the education to address these issues, HomeCare Options established two programs:

### 1. High school equivalency degree program.

"We partnered with the Paterson Adult School to develop a high-school equivalency program for our aides," Wessel says. The classes meet Monday and Wednesday nights from 5:30 p.m. to 8 p.m. There were 40 aides in the initial class.

"We don't pay the aides to attend the class, but we do pay for the teacher's salary and FICA expenses, as well as books used in the class," he says.

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The funds to cover the cost of the program come from a customized training grant offered by the state's Department of Labor (DOL), Wessel explains. "It was very easy to show how this program will help our aides further their education and their chances to advance in their jobs and improve their salaries, which means they will continue to be self-sufficient and independent of state assistance."

Of the 40 aides in the initial class, 11 received high school diplomas within nine months, he says. "This was a tremendous accomplishment for these aides because they worked during the day and went to class at night while juggling their family responsibilities."

The program owes much of its success to the person hired to teach the class, Wessel says. "She is a certified teacher who is bilingual in Spanish and is a nurse," he notes. The combination of Spanish and nursing background means that she relates to her students and understands what their work and personal lives are like, he adds.

There is an added benefit to this program: Wessel now has potential employees applying to his agency's home care aide training program specifically because the agency has the high-school equivalency program. "They plan to complete the training program, get hired, and attend the high school equivalency classes."

## 2. Instruction in English as a second language.

"When we started the high-school equivalency classes, we found that some aides' English was not strong enough to learn the material easily," he says. With another grant from the DOL, HomeCare Options offered English as a second language (ESL) classes for employees. Ten employees graduated the first ESL class in May.

"We found that the ESL class makes it much easier for the aide to understand their job, communicate with patients, and go on to other educational opportunities," Wessel adds.

Because the topics used in the class to practice English are the same topics covered in the U.S. Citizenship Test, students who were not citizens prior to the class found the test much easier to pass, he says.

"We've also taken other steps to make it easier for our aides to apply for citizenship by partnering with the local Catholic Services Agency to help aides complete the application," Wessel explains. His agency also pays the fees for the application and test. "We recently had 12 aides become new citizens," he says.

While these programs require planning time

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and funds, Wessel says the efforts are worthwhile. "You can't do just one or two things and say that you've shown aides that you appreciate them. You have to look at what is important to their lives and develop programs that work together to help them develop," he adds.

Not only do these efforts help retain aides for the agency, but Wessel points out that his agency does no recruiting. "Whenever we offer a training class that is required in our state for any person to work as a home health aide, we fill it up. Word of mouth from our own aides rather than advertising is the reason for our success."

An added benefit: Aides gain skills and confidence. They want to add to their education and help HomeCare Options keep good nurses, Wessel points out. "We have more aides each year take advantage of our tuition assistance program that reimburses up to \$1,000 of tuition expenses as they go on to nursing school." ■

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