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INSIDE

FEBRUARY 1999

VOL. 4, NO. 2 (pages 13-28)

American Health Consultants® is A Medical Economics Company

‘Not in my backyard!’ Here’s what to do if neighbors protest your hospice

Execute a well-planned public relations campaign

In 1994, leaders of Hospice Inc. in Stamford, CT, thought they had found an ideal location for a new residential hospice facility. Near an affluent neighborhood stood an elementary school that had been vacant 10 years, perfect for a hospice that would provide low-level end-of-life care.

The leaders of Hospice Inc. set out obtain the needed approvals and rezoning to purchase the city-owned property. **Janice Casey**, MS, president and chief executive officer of Hospice Inc. — now called Visiting Nurse and Hospice Care of Southwestern Connecticut — knew she was in for an uphill battle the moment a group of nearby residents stood up to object the planned hospice during a city council meeting.

“The fear at the time was AIDS,” says Casey. “Although it was not going to be an AIDS hospice, AIDS patients would be cared for there.”

Neighbors claimed AIDS-tainted medical waste would be scattered throughout the neighborhood and AIDS patients would infect the local water system. At every meeting or hearing hospice administrators attended, the same residents were there to shout them down. The furor caught the attention of local media, and the issue began to play out on the front page of the local newspaper and television newscasts.

“At every hearing, there was a major brouhaha from this small group of neighbors,” Casey recalls. “We were constantly in a defensive position. The strain on the organization was incredible.”

Casey and Hospice Inc. found themselves in the middle of an all-too familiar scenario: Residents set on preserving the residential characteristics of their neighborhood rallied around the “not in my backyard” battle cry.

In this case, Hospice Inc. was placed in the same company as landfills and low-income housing. While no one denies the public benefit of such projects, few residents welcome them to their neighborhood.

Despite the city’s approval of the land sale and property rezoning, Casey and her colleagues opted to withdraw their proposal to buy the old school after opponents sued the city to block the sale. The battle lasted

Here's how a hospice won a PR victory

Columbus (GA) Hospice faced opposition to the construction of an inpatient hospice in November 1995.

The hospice sought to purchase a 5-acre lot that was zoned for residential development. Michael Smajd, MHA, asked city officials to rezone the property to allow for the construction of an 18-bed facility.

The city's Planning Commission recommended the property be rezoned to allow the hospice construction. However, nearby residents, who believed the property should be used for new homes, argued the change in zoning was illegal and took the city to court. Smajd's organization prevailed.

Residents appealed lower state court rulings in favor of the rezoning until the Georgia Supreme Court refused to take up the case, ending the legal battle and clearing the way for construction. **(See related story, p. 13.)**

While Smajd endured anti-hospice sentiment, he also took the following steps in the battle with residents that could be followed by others facing similar troubles:

• **Organize a community forum.**

Months after Columbus Hospice made an offer to purchase the property, leaders arranged a meeting with neighbors at a local restaurant. They brought together hospice representatives, local residents, the developer, and architect.

They came with a set agenda that gave involved parties time to address those in attendance and allowed for questions. They shared architectural sketches, gave a historical perspective of the organization, explained palliative care, and a physician explained the importance of hospice care.

Smajd explained to residents how the hospice would be a good neighbor and the developer talked about why the proposed hospice would be a good use of the vacant property.

In the end, however, Smajd admits the meeting did little to sway opponents, but it sent a message to the city council that would be deciding their fate.

"We knew it would play a lot better with the city council if we showed that we were willing to work with neighbors," he says.

• **Organize a coalition of supporters to write letters to city council members and nearby residents.**

This network included members of the hospice board, local physicians, nurses, and families of patients past and present. Letter writers focused on telling council members that the proposed location was a good spot for the hospice and it was a good use for the property.

In addition, Columbus Hospice sent letters to affected residents to explain their plans and inform them about the expected impact it would have on their neighborhood, including noise and traffic.

In effect, Columbus Hospice had developed a carefully targeted direct mail campaign targeted to key community leaders and adjacent homeowners to refute misinformation about the project and tell their side of the story in human and factual terms.

• **Wrote and placed articles about the project in the local press.**

• **Found supportive neighbors.**

• **Developed talking points and presentation materials.**

At every meeting, Columbus Hospice had its architectural drawings available and data from their studies on hand to help explain the project to the city officials, the press, and the public in non-technical and non-threatening terms. ■

two years. The hospice eventually merged with a local hospital system and built its residential facility on hospital property.

While there is no specific formula for getting past anti-hospice sentiment, there are tactics hospice leaders can employ in their efforts to relocate or build new facilities. According to Casey and **Michael Smajd**, MHA, executive director of Columbus Hospice (GA), the key is to apply the elbow grease early on.

"Looking back, we would have, from the beginning, got the public involved in what we were doing," Casey said. Both hospice executives and other business leaders inside and outside the health care industry say the following public relations tactics should be adopted to negate or

soften the effects of anti-hospice sentiment:

• **Educate everyone involved.** Be open with the local media so that reporters understand your position; provide local government officials with details of your plan; and calm nervous residents by providing plans and discussing the project's real impact on their community. Don't forget to play up any economic benefits.

• **Refute misinformation.** Anticipate the type of misinformation that will be spread. For example, common misconceptions about residential or inpatient hospices are AIDS-related. Put together an HIV / AIDS fact sheet to dispel comments about endangering public health.

• **Isolate opponents.** Show that your opponents are separate from mainstream residents. For example, juxtapose their irrational arguments with common knowledge. Counteract arguments that people can become infected with HIV through casual contact with an AIDS patient with information about years of research showing that HIV is spread through the exchange of bodily fluids, such as blood and semen. By doing this and refuting the misinformation opponents are spreading, hospice leaders will be able to destroy their opponent's credibility.

• **Offer a Q&A.** Give residents an opportunity to have their questions answered and concerns addressed in informative, non-threatening community forums hosted by the hospice director and staff. **(See related story, p. 14.)**

In the end, the only sure way to prevent neighborhood opposition is to avoid building on property that has to be rezoned or purchased from a municipality, both Casey and Smajd say.

"The fact that we had to go through so many hearings gave neighbors more opportunity to attack us," Casey says. ■

Hospice caregivers play role in spiritual care

Don't rely only on chaplains to meet spiritual needs

It's fair to say health care workers know far more about the physical and medical needs of patients than their spiritual needs. With hospice's focus on holistic care, a patient's spiritual needs must be addressed in addition to medical necessities to ensure a peaceful death.

The problem is that many hospice workers are ill equipped to handle a patient's spiritual needs and often defer that responsibility to the chaplain. While the chaplain plays a leadership role, it often falls to nurses and social workers to nurture a patient's spiritual discovery, perhaps even help the patient to examine his or her own spirituality despite initial indications that spirituality is not an issue. In many cases, the nurses or social workers receive the first signals of spiritual yearning, leaving them to nurture the patient's inquiries until the patient asks to see the chaplain.

The search for spirituality often heightens as death approaches, causing patients to express their longing for spiritual understanding in formal and informal ways. Patients may openly question their beliefs and seek out the advice of a hospice chaplain and, in many cases, they may subconsciously show signs of spiritual struggles. In the latter case, it falls upon the nurse or social worker to encourage an open discussion of spirituality. Failure to do so leaves care short of hospice's holistic care approach.

The first step in meeting patients' spiritual needs is training hospice staff about spirituality. Hospice chaplains play a large role in helping nurses and social workers understand the concept of spirituality.

The most important message, says **Jeanne Brenneis**, MDiv, STM, director of Bioethics Center and chaplain at Hospice of Northern Virginia in Falls Church, VA, is that spirituality comes in different forms and may not include a formal religion.

"Spirituality is any human being's sense that is beyond self and beyond human," she says. "It can be a sense of God, sense of universe, or a sense of one's connection with the universe."

According to *Death Studies,* a 1990 study of death and dying, spirituality is concerned with the transcendental, inspirational and existential way to live one's life as well as concerned with the person as a human being.

"The common denominator is the search for meaning in life," says **Jay Stark-Dykema**, MA, pastoral counselor with CareMed in Chicago. "It's the understanding of one's place in the universe."

One of the important lessons in understanding spirituality is that it is a concept so diverse it encompasses both secular and religious beliefs. Caregivers must be able to recognize spiritual needs that fall outside their own belief system. For example, a nurse who comes from a Christian background must be sensitive to a patient who

finds spiritual meaning in a garden or fishing. **(See related story, p. 17.)**

Brenneis and Stark-Dykema offer the following advice to help hospice managers and staff understand and become more sensitive to diverse spiritual needs:

1. Provide training in other faiths.

As part of new employee training and ongoing inservice training, nurses and social workers should receive training in other faiths. This should include the rituals and traditions of different religions and beliefs.

Caregivers working with patients having an affiliation with an organized religion, such as Catholicism, need to understand the rituals and traditions associated with being Catholic.

Take the case of a Catholic man who has divorced and remarried. The Catholic Church doesn't recognize his second marriage because the first wasn't annulled. For this reason, the dying man may feel separated from his church and have a need to be reconciled with his church. A caregiver who is not Catholic may not readily spot signs of spiritual distress. A caregiver trained in the basic tenets of the Catholic Church would be able to encourage the man to discuss his feelings with a priest or chaplain. **(See related story on hospice programs designed for patients of specific faiths, p. 19.)**

Understanding the rituals and traditions from a secular perspective will also be valuable to caregivers as they try to meet the spiritual needs of those who do not have strong religious ties.

"Gardening, for example, is spiritual for some," says Stark-Dykema. "They may find order in the universe through the annual planting and watching things grow. They may find peace by taking a walk in the woods."

While neither gardening nor nature hikes are associated with a formal religion, they are part of the rituals and traditions of an individual.

2. Don't proselytize.

It's easy to impose one's own beliefs on another. It even can be done unintentionally. If caregivers understand their primary responsibility to provide whatever spiritual care the patient indicates or is most compatible with their current belief system, the chances of imposing inappropriate spiritual care is reduced.

"Our job is to listen to the patient so their religious beliefs are understood," Brenneis says.

Using the same Catholic man as an example, a nurse with a Protestant background imposes her belief system on the man if she simply turns a deaf ear to his concerns about his past divorce and how it affects his standing in the church. Her belief system tells her that divorce does not prevent a subsequent marriage from being recognized by her church. If her response to the man's concern is, "I think God understands," she is imposing her beliefs on him. She would be doing the patient greater service by encouraging him to talk with a priest or chaplain.

"Listen to his beliefs and how he relates to his church," Brenneis advises. "Ask the person if he wants reconciliation with his church. Understand a patient's needs as the patient perceives them."

3. Establish relationships with community clergy.

Community clergy, along with the hospice chaplain, can provide a wealth of information regarding various faiths and can act as resources when questions arise. Even more important, community clergy can be matched with patients of specific religions or denominations to better meet patients' spiritual needs.

4. Explain the role of nurses, social workers, and volunteers.

While caregivers are often the first contact in a patient's spiritual search, they are by no means the last. During new employee orientation and inservice training, chaplains must make other disciplines aware of their role in meeting a patient's spiritual needs.

"What's important is the nurse recognize the chaplains' work," Brenneis says. "Caregivers need to know they need to use the chaplain."

The role of caregivers is to act as a bridge between the patient's own spiritual yearnings and the spiritual care that can be provided by trained chaplains. It's important for nurses and social workers to understand how to encourage hospice patients to seek spiritual care from a chaplain.

Brenneis offers the following example: While a nurse is caring for a terminal cancer patient, the patient begins to openly question her impending death. "Why is this happening to me? Is God punishing me?"

The nurse responds, "I don't know what to tell you. But the chaplain can talk with you about that."

If the patient has been unwilling to seek out the chaplain in the past, she is likely to be put off by the nurses' response and perhaps even keep her questions about spirituality to herself.

Instead, the nurse should have responded: " I really think you should talk with our chaplain. He's here to listen and he won't preach. I'll have

him call you to set a time when he can stop by."

5. Perform a spiritual assessment at admission.

Just as a physical and medical assessment is performed at admission, a spiritual assessment should become part of the admissions and care planning process **(See spiritual assessment tool, p. 18.)**

6. Adopt an integrated approach to spiritual care.

Understand that everyone on the hospice care-giving team plays a role in meeting a patient's spiritual needs. Use multidisciplinary team meetings, which should include hospice chaplains, to discuss patient's spiritual needs.

Sometimes, patients deny visitation of a chaplain, leaving the nurse or social worker to handle the lion's share of spiritual care. Those caregivers should keep the chaplain informed about the patient's spiritual condition so the chaplain can provide needed direction.

In the end, Stark-Dykema says, nurses, social workers, and volunteers are providing spiritual care even when they don't know it. "The process of providing care in a hospice and just being there for the patient is a form of spiritual care." ■

Nursing home uses spiritual assessment tool

Caregivers must include spiritual needs

Getting staff to recognize the importance of meeting the spiritual needs of patients is one thing, but gathering patient information about spiritual needs and using it to help develop an overall care plan is quite another.

Ingleside Skilled Nursing and Rehabilitation Center, in Mount Horeb, WI, uses a spiritual assessment tool congruent with the minimum data set (MDS 2.0) to help determine each resident's spiritual needs.

"Far less is known about the human spirit than is known about the body and the mind, says **Sue Schoenbeck**, RN, former director of resident care at Ingleside in a paper describing the assessment tool. "Issues of the spirit are important when caring for the elderly in long term care environments, as well as preparing residents, families, and staff for the death of a resident. . . . It is judicious for the care-giving team to gather information about spiritual as well as physiological, mental, and psychosocial needs."

Ingleside's spiritual care program is rooted in a theory of logotherapy developed by **Viktor Frankl**, a Viennese psychiatrist who survived several World War II concentration camps. Frankl theorized people can find meaning in life's events, including suffering and death. He believed people search for meaning in life up to and often through the death event.

With this in mind, caregivers must ask patients and their family members questions regarding spiritual needs, says **Carol Gabor**, BSW, a social worker at Ingleside. The open discussion allows residents and their families to feel at ease about sharing their spiritual side. It becomes the caregiver's responsibility to collect information regarding a patient's spiritual needs and incorporate it into the overall treatment of the patient.

The assessment tool

The first part of Ingleside's spiritual care assessment tool focuses on information from the resident's concept of a god or deity, religious practices, and helping others. "This tells us if they have a religious background and what types of services they want," Gabor says. "One thing we have seen is every situation is different, and this assessment tool acts like a guide for each individual case. It gets the resident, family, and caregiver focused on spiritual needs."

Part II of the spiritual assessment tool engages the resident in conversation about sources of help and strength, relation between spiritual self and health, and impending death, says Gabor.

"This part gives me a good handle on whether they're ready for [spiritual care]," she says. "It tells me how much support we need to provide."

Once the caregiver has completed the resident interview, information from the spiritual assessment tool is incorporated into the individual's care plan. For example, when a resident says prayer is a daily part of his or her life, staff should include "provide private times for prayer" in the care plan.

Schoenbeck uses the case of an Alzheimer's patient as an example. "A resident with Alzheimer's disease for whom evening prayer had been a ritual can be guided by staff each evening in this routine," she wrote. "Staff can assist family members to record familiar prayers to play back to

(Continued on page 19)

Ingleside Spiritual Assessment

Part I: Activities

Name: _____
Medical Record # _____
Date_____

Concept of God

- Is religion or a god important to you?
- Is prayer helpful?
- Does a god play a role in your life?

Customary Routine: Involvement Pattern

- Do you find strength in your religious faith?
- Do you usually attend church, temple, synagogue, etc.?
- Are there any religious practices that are important to you?

Religious Practices

- Has being sick made any difference in your religious practices or prayer?
- What religious books or songs are helpful to you?
- Have you participated in/would you be interested in a Bible study group?

Helping Others

- Do you enjoy helping others?
- In what ways have you helped others?

Recommendations for Care Plan:

_____
_____
_____
_____

Assessor's Name _____
Title _____

Part II: Social Services

Name _____
Medical Record # _____
Date _____

Sources of Hope and Strength

- Who is the most important person to you?
- Are there roles you had in your life before that are now closed off to you?
- If so, how do you feel about this?
- What has given your life meaning?
- What gives your life meaning now?
- In what ways do others help you?
- What helps you most when you feel afraid or need special help?
- What is your source of strength or hope?

Goals

- What are your personal goals?
- Do you want to participate in and/or assist with religious services at Ingleside?

Relation Between Spiritual and Health

- What do you think is going to happen to you?
- Has being sick made any difference in your feelings or beliefs about God or religion?
- Is there anything particularly frightening or meaningful to you now?

Impending Death

- Do you want a bedside service? __ No __ Yes
- Clergy: Your own? _____
- Parish _____ Phone _____ Other? _____
- Do you want it in your room or chapel? _____
- Do you wish to be present or would you prefer it be held without your presence?
- Are there any special words, prayers, songs, or thoughts you would like expressed at the service?

Recommendations for Care Plan:

_____
_____
_____
_____

Assessor's Name _____
Title _____

Source: Ingleside Skilled Nursing and Rehabilitation Center Inc., Mount Horeb, WI.

their loved ones. Furthermore, resident prayer and hymn requests can be incorporated into a weekly non-denominational service."

If the assessment shows the resident is experiencing spiritual distress, care plan approaches may include pastoral counseling, psychotherapy intervention, and medication regimen evaluation.

Caregivers should not assume, however, that residents' feelings will remain static. "Entering a nursing facility does not mean a person stops growing and changing," Schoenbeck wrote. "Residents often re-evaluate and change what they value. Therefore, spiritual needs must be regularly monitored, and changes to the care plan made accordingly to guide staff in providing the support the resident needs."

Bedside closure service

One of the services Ingleside offers its residents is a bedside closure service. As a patient's death approaches, the patient and family have heightened spiritual needs. Staff, too, will have intensified needs because of their close interactions with residents.

To address resident, family, and staff needs, Ingleside holds a bedside closure service to comfort those left behind. Part II of the assessment tool provides information about whether or not a resident and family want a service and what they would like incorporated into the service.

"The service is designed not only to honor the resident in the manner requested, but to give staff the opportunity to say good-bye and to share with family, friends, and the departed some of the good times experienced together," wrote Schoenbeck.

Schoenbeck recalled one bedside closure service for a man who communicated only by repeating two syllables. At the service, certified nurse assistants (CNAs) told family members how they had learned what the resident wanted by his intonation of the two syllables. Another CNA thanked the family for the opportunity to care for a man who inspired her she wanted to make a career of helping people with speech impairments. A housekeeper commented he would miss joking around and seeing the resident's broad smile.

Ingleside staff assembled a bedside closure service guide that includes some of the songs and prayers most frequently requested by the facility's population. This guide is printed in large type for ease in reading. A staff-written prayer book is given to each new resident and staff member to help people find words with which to pray together.

Program benefits

In 1995, Ingleside conducted a study measuring the value of its spiritual care program for residents, families, and staff. Results shows the program led to increased knowledge of and response to residents' spiritual needs. Impending deaths were more openly discussed, leading staff to communicate with residents about their last wishes. The quality of life near death was enhanced as individual wishes were honored.

"The staff has become more invested in patient care," Gabor says. "Patients become people to them, people with a past, people with value." Families also have benefited. Positive written responses have been received from the families of residents for whom a bedside closure service was held.

One daughter responded in the survey: "We felt the service for Mother was helpful and thoughtful. We felt she was liked and respected although we know she was a trying woman."

(Editor's note: The Schoenbeck article and Ingleside survey are available on the Internet at www.efmoody.com/longterm/spiritual.html, a consumer resource Web site.) ■

Programs address cultural, religious needs

The growing number of patients from culturally and ethnically diverse communities has caused some hospices to create programs designed to answer the specific needs of patients of different religious faiths.

Hospice of Michigan, in Southfield, MI, has two special religious programs, Jewish Hospice Services and Islamic Hospice Services. While on the West Coast, the San Francisco-based Zen Hospice Project (ZHP) answers the spiritual needs of its patients with Zen Buddhist principles.

Hospices that address the religious needs of their patients are gaining popularity in the communities they serve. Experts say hospices and home care services can implement these kinds of programs by reaching out to community centers, or coordinating their services with religious

organizations within these communities. **(See related story on addressing the spiritual needs of hospice patients, p. 15.)**

The Jewish model

Patients enrolled in Jewish Hospice Services have a wide network of support. The program is affiliated with 14 different organizations ranging from the local Jewish hospital to local chapters of the National Council of Jewish Women and Kosher Meals on Wheels. Reaching out to Jewish patients with special needs, the hospice service offers assistance to Holocaust survivors, children, the developmentally handicapped, AIDS sufferers, residents of adult foster care homes, and indigent and isolated individuals.

Rabbi E. B. (Bunny) Freedman manages Jewish Hospice Services of Southfield, MI, sponsored by Hospice of Michigan and Jewish Family Services. Patient-directed, it is open to all Jews, from the most orthodox to those unaffiliated with a synagogue or Jewish organization.

The program serves 20 to 30 patients daily, providing them with medical, social, and spiritual aid. Committed to the principles of palliative care, the medial and nursing staff are either Jewish or taught Judaic traditions and rites. Most volunteers are Jewish.

Hospice staff entering a patient's home must follow the family's direction and guidance regarding dietary practices, Sabbath and holiday customs, attitudes toward God, and other spiritual issues. Freedman has administered the program since its inception six years ago. For him, "reconnecting" patients with their religious community, synagogue, or rabbi is the most important part of his work.

"Many people go through life without much religious attachment, or they've lost touch with their belief," Freedman explains. "When they get to the end of life, they often change but are afraid to call on their rabbi or synagogue. That's when I step in and re-establish the contact. Dying is a painful experience — emotionally too. It is my job to make it easier for our patients and their families so that they don't have to face it without spiritual help and loving support."

The Islamic model

Dan Layman, MBA, manager of the Islamic hospice program, has seen a constantly rising demand for this service. With a population of about 300,000 Muslims in the Detroit area, the need for hospice service that incorporates Islamic traditions and rites became obvious six years ago. The Islamic hospice service was organized in 1996 and has since cared for 20 to 25 patients annually.

"We try to reach out to all patients of Islamic faith, which gives us a wide spectrum of Muslims — from those who are Muslims by name only to those who are devout Muslims," says Layman. "This also brings us in contact with many different cultures, because our patients come from all Islamic countries, anywhere from Pakistan to Africa and from every Arab country in the Middle East. We also serve African-Americans who are Muslim."

Though the hospice employs six medical directors, most of the medical assistance within the program is offered by one Muslim physician and two Muslim nurses. All staff and volunteers have to go through an eight-hour training session, which includes lectures on Islamic religion, culture, and tradition. According to Layman, most volunteers are Muslim, many functioning as translators for Farsi and Urdu, and the Arabic tongues of Syria, Jordan, Iraq, Lebanon, and Egypt.

Depending on the request of the patient or family, the care is administered according to Islamic practices, avoiding cross-gender contact. At their request, patients will be visited by an Imam who leads them in prayer and reads the Koran. All hospice staff and volunteers must be familiar with the significance of basic Islamic rules, such as removing shoes before entering a home and administer "Vozou," the ritual washing before engaging in religious rites.

The Buddhist model

Largely in response to the exploding AIDS crisis in 1987, **Frank Ostaseski**, a Buddhist, founded ZHP as a part of the San Francisco Zen Center. Today, ZHP operates a residential hospice program that offers care in a four-bed "guest house," a renovated Victorian home, and a 28-bed hospice unit in the Laguna Honda Hospital, the nation's largest public long-term care facility.

Before ZHP, patients without home nor family who lingered in the final stages of AIDS, cancer, or other diseases, would end up in the acute-care center at San Francisco General Hospital. If they did not die there, they would be transferred to a non-hospice unit at Laguna. Without a permanent address, these patients could not draw government entitlements. By offering them the address

SOURCES

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of the Zen Guest House, they became eligible for hospice home care; and through collaboration with Hospice by the Bay in San Francisco, ZHP now provides comprehensive medical management and 24-hour hospice care.

The staff at ZHP works closely with an interdisciplinary team of volunteers, physicians, nurses, social workers, nursing assistants, activity therapists, nutritionists, and spiritual and bereavement coordinators. A major component of the ZHP is public education and professional training for health care providers. ZHP has arranged workshops and retreats to share its approach to the care of AIDS and cancer victims with professionals in this country and abroad.

According to Michael Vargas, MSW, residence manager of the guest house, this approach is built on a philosophy influenced by the Buddhist principles of "mindfulness, loving kindness, dedication to the service of others, and acknowledging the impermanence of life."

Meditation and the "search for stillness in chaos" are recommended, but not required. Sometimes, patients accept meditation and introspection after having been exposed to skillful touch, rhythmic breathing, or massage, says Vargas.

"While we expose our patients to Buddhism and its principles, specifically to the Zen practices, we make no attempt to convert anyone," says Vargas. ■

SPECIAL REPORT: Hospice in Prison

(Editor's note: About 1.8 million people are incarcerated in the United States, and the prison population has been increasing by 50,000 to 80,000 people a year. Even more striking is the statistic that the nation's incarceration rate has quadrupled since the mid-1970s to 445 per 100,000, and nearly 1,000 prisons and jails have been built within the past 20 years.[1] This special report details a variety of efforts made across the nation to provide hospice care to dying federal, state, and county prison inmates. Inside this issue, you also will find articles about prison hospice volunteers, a Pennsylvania hospice's training program, and a model Texas prison hospice.)

Growing prison populations will need hospice care

Hospice brings a little compassion to inmates

More than 20 states have or are planning programs that will incorporate the hospice concept in prisons and prison hospitals. Experts say this type of hospice work will increase the next few years as the prison population grows dramatically, resulting in many inmates dying behind bars.

The National Commission on Correctional Health Care (NCCHC) in Chicago and the National Prison Hospice Association in Boulder, CO, have had an increase in phone calls from hospices and prisons interested in starting new programs.

"The hospice movement is growing and becoming more important," says **Judith A. Stanley**, MS, CCHP, director of accreditation for NCCHC. "Because of the increased number of long sentences and life sentences, and the increased number of individuals coming into the system with HIV-positive status or cancer, the prison population is a particularly vulnerable population."

The National Prison Hospice Association (NPHA) has been developing guidelines for prison hospices to help organizations meet the growing need for end-of-life care among the inmate population, says **Elizabeth Craig**, executive director of NPHA.

The increasing number of prisoners has also meant more people are dying of diseases in prison; some hospice officials say this points to a need for hospice care.

With the advent of AIDS, the death rate of prison inmates rose sharply between 1990 and 1995. However, this has dropped in recent years because of the success of protease inhibitors and combination antiretroviral therapies, according to **Allen J. Beck**, PhD, chief of Corrections Statistics

at the U.S. Department of Justice in Washington.

Prison hospice work is being conducted in a wide variety of ways. Some freestanding hospices provide full hospice services to prisoners. Others only provide volunteer or training services. Still in other cases, the prisons themselves or their health care providers have formed their own hospices that serve the prison population.

Some prison hospices are funded by federal or state funds or are part of the prison medical services contracts. Other hospices contract to provide services to prisons. Others provide these services at no charge. Prison hospice experts say that no matter what the financial arrangement between a hospice and prison, this is not a money-making enterprise.

Bringing hospice inside

Hospice Care of Broward County in Fort Lauderdale, FL, has perhaps one of the most evolved prison hospice programs, which it provides at no charge. The agency formed a partnership in 1989 with Broward Correctional Institute, a maximum security state prison for women in Pembroke Pines, FL. **(See related stories, pp. 23-24.)**

"We identified an unmet need and started out slowly by providing a support group and education for HIV / AIDS residents at the institute," says **Pat Byrnes**, administrative assistant with the hospice. "Then we increased that effort and prepared inmates for the Impaired Inmate Program, where we trained inmates in the facility to be caregivers for inmates who were ill in the infirmary."

This evolved into a full-fledged hospice program after the hospice worked with prison officials, including **Elizabeth Vogt**, MA, human services program director. Now nurses and other hospice staff, including aides, social workers, and chaplains, regularly visit dying inmates, providing the same services they would provide to a dying person in the community.

State money to pay for hospice care is scarce, so the hospice's voluntary help is appreciated by both inmates and the prison administration, says **John A. Anderson**, correctional superintendent for the Broward Correctional Institution.

"It helps the whole prison community by dealing with significant health issues that are most likely terminal," Anderson says. "We do have to create a humane environment within prison, and this helps us meet that mission."

Volunteers among the inmates are given eight hours of hospice training and are closely supervised as they begin to help the dying women in activities of daily living, such as eating, ambulation, and housekeeping duties, Vogt says. The hospice training also dispelled some of the inmates' ignorance and hysteria about terminal diseases.

Hospice tailored for prison

Inmates who volunteer for hospice work have no external motivation, and choose to volunteer only to gain some personal satisfaction from the work, Vogt says. "They all have a full-time job in the prison, and they do this in addition to that."

The prison has about 20 inmate hospice volunteers, and the dying population has fluctuated between one and five inmates.

"We took the hospice model and tried to tailor it to fit into the prison system," Vogt says. "We provided a lot of time and energy into educating medical and security staff into the concept of having other inmates caring for dying inmates."

The prison staff has responded quite positively to the hospice work, says **Anne Watts**, RN, a patient family care coordinator and nursing supervisor. Watts visits the dying women prisoners.

"The prison nurse practitioners have conferred with me on several occasions to see if they were doing the right thing as far as managing symptoms or problems," she says.

One big challenge is educating the prison staff about the hospice concept and its approach to palliative vs. curative care.

"You also must understand the safety and security issues involved in working with inmates," Watts says. "You cannot bring anything in with you; so you can't bring a hospice patient a little something, and you can't bring anything out of the prison."

Also, hospice nurses cannot reveal any information to prisoners. For example, if a hospice nurse knows that a dying inmate will be transferred to an infectious disease unit, the nurse cannot mention this to the patient.

Vogt and other prison mental health workers provide an escort to hospice staff in the prison. Dying inmates are housed in the infirmary when they need medical attention. When they're medically stable, they stay in the regular dormitories, which they would not be able to do if hospice staff were unavailable to monitor their health, Vogt explains.

When hospice workers visit terminal inmates

who are living in the two-bed dorm rooms, the patient and hospice employee can meet privately in a mental health office, Vogt says.

Finding staff who are willing to visit patients in a prison setting also can be difficult.

"Some people wouldn't go into the prison if you offered them a million dollars," Watts says. "Then there are others whose eyes light up, and they say, 'I'd like to do that.'"

The hospice employees' presence has been a great service to the prison staff and inmates, Vogt says.

"They provide some expertise on death and dying and pain management, and they consult regularly with our physicians," she explains. "And just the fact that someone from an outside agency is coming to see these dying inmates helps their morale and helps them improve physically."

Watts, who formerly worked as a corrections nurse, has experienced some personal benefits from this service. Last Christmas, she had a 38-year-old terminal patient with eight children. The woman's family was very poor and she was concerned her children, ranging from ages 5 to 18, wouldn't have any Christmas gifts.

"We put together a big basket of gifts for her children," Watts recalls. The hospice staff chipped in to buy the gifts and took photos of the presents before sending them to the patient's family hundreds of miles north of the prison. The hospice staff then obtained permission from the prison to show her the photographs.

"That was one of the few times I saw her smile," Watts says. "It lifted her whole spirit, and she was a different person; it even contributed to her condition improving somewhat."

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Texas prison provides compassionate care

Prison hospice brightens inmates' last days

When a dying inmate enters the Michael Hospice Facility in the maximum-security Texas Department of Criminal Justice facility in Tennessee Colony, he sees bright, creative murals of landscapes, water scenes, and even a New England shoreline. His room is white with one wall painted in a soothing, pastel color. If he needs a change of scenery, he can look at a patio that was built with bricks and decorated with plants.

The hospice, formed two years ago by the state criminal justice department, has 21 beds and typically has a census of about 18 patients, says **Jo B. Green**, MS, associate clinical psychologist in the prison's Michael Unit.

A prison hospice can be a good thing for dying inmates, often even better than compassionate release, she says.

"These patients have been incarcerated for a long time, and some have been out of touch with their families," Green explains. "We don't want to turn terminally ill incarcerated people into terminally ill homeless people."

A prison hospice operates differently than a free-world hospice because it is subject to prison rules and security constraints, Green says.

However, the Michael Hospice focuses on quality of care and allows patients to have visitors, even children, seven days a week. The hospice contacts a patient's family upon arrival.

"Visitors can't bring personal items to the patient, but they can make deposits to the prison commissary account and buy things out of the commissary," Green says.

The hospice was built in a hospital-like setting that has been transformed by murals painted by inmates. "We didn't get any more money than a normal infirmary, but we were able to be creative," she says.

Here is how the hospice works:

- **Reimbursement:** There is no third-party reimbursement. The hospice is the result of an integration of the University of Texas Medical Branch in Galveston, TX, managed care, and the 3,100-bed prison. Green is an employee of the University of Texas Medical Branch, which is the contract medical provider of the prison.
- **Dying population:** The dying inmates typically suffer from cancer, HIV / AIDS, or liver disease caused by hepatitis. "These guys' bodies are not in really good shape," Green says. "They've abused their bodies all their lives and now they're incarcerated."

The dying population is getting older due to longer prison sentences. Dying inmates stay in hospice care for an average of 81 days, she adds.

- **Security issues:** "The cooperation we have

with our security is absolutely essential," Green says. "They are our gatekeepers, and we don't have any amenities without their approval."

For example, the hospice's Christmas party had to be approved by the prison warden, and anything unusual done for a patient has to be approved. One patient considered his dog his family member, so prison officials gave permission for the hospice to bring the man's dog in for a visit.

"This is the warden's house, and we're guests," Green says. "Nothing comes in and out without the warden's approval."

• **Spirituality:** The hospice helps dying inmates accept their illness and come to terms with their lives. "Obviously, their lives didn't work out the way they expected, because they are here, dying in prison," Green says.

However, this lack of freedom and material comforts can serve as a springboard that allows a patient to grow spiritually because the spiritual component of their lives is about all they have left, she adds.

• **Volunteers:** The Michael Hospice uses inmate volunteers. The prison chaplain's office identifies potential volunteers, and inmate volunteers refer other inmates to the hospice. The inmates know exactly who would be a good volunteer because they live with these people 24 hours a day, Green says.

"When we have a volunteer applicant, we run his name by the other inmate volunteers," she adds.

• **Training:** Inmate volunteers participate in a 30-hour training program and receive on-the-job training by the hospice staff.

"We also meet weekly to discuss the issues," Green says. The hospice currently has 14 inmate volunteers who provide all the care and activities of daily living assistance that a family would provide for a hospice patient.

• **Palliative care:** Patients receive palliative care, if they desire. All narcotics are counted at the beginning and end of each shift, and all medication is kept in medical custody until presented, Green says.

"Patients do refuse it sometimes, and that's documented."

The keys to the narcotics are closely guarded and monitored, and offenders are not allowed in the doorway of the room where they are kept. "That's another consideration of how it would be different from a hospital," Green adds. "We probably keep closer tabs on our narcotics." ■

Hospice trains volunteers to care for inmates

Volunteers give inmates compassion

In Charles Dickens' *A Tale of Two Cities*, there is a scene in which the wife and daughter of a French expatriate, who has been sentenced to the guillotine, pace below a prison window in hopes that he will have a fleeting few seconds to look out and see his loved ones.

That glimpse gives the doomed man courage when hope is pointless.

The Rev. Paul Guoan, a Jackson, MI, Catholic priest, has witnessed a similar scene set in modern times. A 40-year-old man, dying in the Michigan prison, has a grandfather who is an inmate in the same prison complex.

The dying man, to whom Guoan provides volunteer hospice care, has rare opportunities on some days to look out of a prison hospital window and see his grandfather walking in the prison yard below.

The dying prisoner has shared with Guoan some letters his grandfather has written him. This is the only way they are able to communicate with each other. The letters contain poor grammar and misspellings, but they are spiritual treasures that encourage the grandson to be a good person at the end of his life, Guoan notes.

"The grandfather has been in prison all of this man's life," he says. "And these letters are precious things."

Alleviating fear of death

Guoan provides hospice care to nine dying prisoners. His work is part of an outreach program that the Hospice of Jackson began about 10 years ago.

"It was an effort to reach out to the prisons through our volunteers," says **Michael Freytag**, MA, LPC, NCC, executive director of the hospice, which is a wholly owned subsidiary of Cascade Health System, also based in Jackson.

The prison contains an acute care hospital that provides health care for the dying inmates. The hospice provides no clinical care. "We send volunteers in to meet the emotional and psychological needs of the terminally ill within the walls of the prison," Freytag says.

Volunteers undergo 20 hours of hospice training

and have a special orientation at the prison. The orientation covers the prison's protocol for coming and leaving and bringing in outside items. Also, volunteers must have inmates sign a release that they will accept a hospice volunteer's visits.

The volunteer service complements the hospice's mission to provide a growth experience to people at the end of their lives, Freytag notes.

"The core of what hospice is about is to alleviate the fear, to help bring some understanding, and to help the person find reconciliation within himself."

Staff help forgiveness

Guoan has found that dying inmates first want a chance to vent the anger they've carried around since their often abusive childhoods.

"You feel that toxin coming out of them," he says. "They can let go of the hurts of the past and the anger, knowing [they're] not going anywhere with it."

The men often blame their families, friends, and even the governor for their problems, he notes. Eventually, some inmates begin to acknowledge their responsibility and how they have victimized others.

Also, the men initially want Guoan to help them with their legal appeals. However, Guoan makes it clear to them he is there only for their spiritual well being. He says that despite his clerical collar, he sometimes must make several visits before inmates trust him.

Once the dying men exhaust the litany of their pains and complaints, Guoan tries to steer them to the positive aspects of their lives, without dwelling on what brought them to prison. He also offers them an opportunity to ask for forgiveness, and reassures them that anyone who wants reconciliation with God may have it, and the past is forgiven.

"Once they know they've been forgiven, it gives them a whole different kind of hope," Guoan says. "When I come in to visit, we're past the anger and the fear. It's just like a friend coming to visit."

Sometimes the men ask him to read them the Bible, or they may entrust him with their last belongings.

One man wore a Catholic scapular, which has pictures for spiritual inspiration. The night the man was dying, he asked Guoan for a favor: "Father, will you keep this? They'll just throw it away after I die." ■

Pennsylvania hospice trains prison staff

A Pennsylvania hospice counselor combines her passion for hospice work and interest in justice by becoming a hospice instructor for prison staff.

With training, prison guards and employees find compassion for dying inmates, even when it goes against their personal prejudices about prisoners' "deserve," says **Phyllis Taylor**, RN, an educator and counselor with the Hospice of the Delaware Valley in Plymouth Meeting, PA.

Taylor recalls how one guard became angry during her hospice orientation class.

"She said, 'Why should these folks get special treatment? My brother died several years ago, and we didn't get any help.'"

"You're right to be angry that your family didn't have hospice care," Taylor replied. "They should have had support. Somebody should have told you about hospice."

She suggested the guard receive bereavement help from hospice, just as the inmates should receive hospice care.

"I was trying to take her anger and reframe it in a way that identified her anger in a way that I think was valid," Taylor says. "I think it's terrible that she and her family did not have access to hospice, but that doesn't mean that inmates shouldn't have hospice too."

Genesis of a program

Taylor serves as a consultant and educator for the Philadelphia Prison System, which has more than 6,000 inmates.

Although the system is a county facility and not a state or federal penitentiary, inmates can be held there for up to 23 months after sentencing, she explains.

Taylor approached local prison officials after she heard of an inmate who was dying from AIDS. When she explained hospice care, the prison officials seemed interested. But the next time Taylor called them, she learned the dying prisoner had been transferred from the hospital back to the general prison population.

"That's when I began to say, 'Wouldn't it be good to be able to have some form of a hospice program in the prison?'" Taylor recalls. The warden agreed and asked her to teach every

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correctional officer in one building.

In the past year, she has held one half-hour inservices for correctional officers, and conducted two-hour inservices for officers assigned to the medical unit. She also has trained social workers, clergy, psychiatric workers, AIDS workers, and even union representatives for some of the staff.

In all, Taylor has conducted 24 hours of educational meetings and formal instruction. She's also spent her own time developing training materials.

Taylor handed out a one-page hospice guide to correctional officers and a longer guide to staff at the two-hour inservice. **(See hospice care handout, inserted in this issue.)**

"We want people to really understand this," she says. "My desire is that people know there is a real need in the jail system for hospice care."

Families play a role

The system pays the hospice a limited amount for Taylor's training and consulting time, but there is no money for other hospice services, she adds. "Also, I am a nurse, counselor, and part of the bereavement team."

Now that the staff has been trained, the next step for the Philadelphia Prison System is to admit inmates into hospice care. Taylor plans to meet with the inmate block captains to discuss hospice care with them as well. Then, she'll help the staff get the program off the ground and later serve as a consultant.

Taylor suggests other hospice staff interested in becoming involved in prison work begin by contacting the warden. If the prison's health care is provided through a contract with a health care system, they would have to contact those officials as well.

One place to start might be the formation of a bereavement support group for inmates' families, Taylor suggests. Even these groups would require cooperation with prison officials because the hospice would need to obtain permission from inmates to contact their families.

Hospice prison work may cost hospices money, but it is worth the cost and effort, Taylor says.

"I go back to the basic premise of hospice as I knew it 25 years ago when money was a major concern because there was no financing," she adds. "I think it's the right thing to do." ■

COMING IN FUTURE MONTHS

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Hospice's pet therapy program works well

All it takes is a little Sugar

Hospice of Naples Inc. in Florida started a pet therapy program for hospice clients in hopes of brightening patients' days and making them more comfortable with hospice staff.

"We'd been wanting to do it for a long time. Then, we received some money from a local veterinarian," says **Diane Cox**, president and chief executive officer of the hospice, which serves Collier County on the southwestern coast of Florida.

First, the hospice needed to find the right dog for the job. The hospice formed a committee called Pets Are Wonderful Souls (PAWS). The goal for pet therapy was to comfort hospice patients through a dog's visit, and help change a patient's focus from discomfort to pleasure.

Filling the bill

They found the perfect dog for the job: Sugar, an English springer spaniel with big eyes and black and white fur, fit the bill perfectly. Sugar had belonged to a former hospice nurse and now needed a new home.

Hospice officials decided to place Sugar in a six-bed residential home, says **Roberta Towle**, MSW, LCSW, former assistant director of psychosocial services for Hospice of Naples, and current director of social services at the North Georgia Medical Center in Ellijay, GA. Sugar is with her now, and the Hospice of Naples is working on finding a replacement.

Finding her limits

Sugar had full run of the residential home, and she was treated affectionately by both residents and staff. After a month, however, it appeared something was wrong with her, Towle says.

"Those of us who were nurses said the dog was sick, and those of us who were pet people said the dog was depressed," Towle says. "Sugar really had no mother figure, and would become very attached to most of the residents. When they died, [she] was losing people who loved her."

The solution was to give Sugar a home away from the residential home. Towle brought Sugar home to join her two dogs and five cats. It worked.

Then Sugar's duties changed to being a pet therapist for hospice patients who wanted to see her. Towle brought her along on visits, often finding that Sugar was able to work emotional miracles.

Working a miracle

One bedridden elderly woman, for example, had a negative attitude and needed constant oxygen administration. Towle brought Sugar to the patient's home after receiving a call from a daughter who said that she might be dying.

"As soon as we walked in, Sugar went up to the woman and put her head on the woman's bed, causing the woman to smile," Towle recalls.

Sugar wanted some water, so they took her to the kitchen. Suddenly, the bedridden woman took off her oxygen tubes and climbed out of bed. She walked without assistance to the kitchen and began to pet Sugar as though this was her normal routine.

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

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Subscription rates: One year (12 issues), $299. Outside U.S., add $30 per year, total prepaid in U.S. funds. One to nine additional copies, $150 per year; 10 or more additional copies, $90 per year. Call for more details. Missing issues will be fulfilled by customer service free of charge when contacted within 1 month of the missing issue date. **Back issues**, when available, are $50 each. (GST registration number R128870672.)

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"The daughter took me aside and said, 'I don't believe this because just a couple of hours ago, my mother couldn't get out of bed or breathe without her oxygen,'" Towle says.

Sugar also had an uncanny way of knowing when patients needed help. Towle often took her to visit residents at the hospice home. If a patient needed help, but didn't have the strength to push the buzzer, Sugar would somehow know and stand barking beside the patient's door.

Once, Sugar even knew before going into a patient's room that the patient had died. Instead of running as she usually did to jump on the patient's bed, Sugar began to run to the room and then stopped right before the door. The woman had just died and her body was still there, but Sugar appeared to sense that the person she had known was no longer there.

Finding the right dog

Not every dog is a Sugar, as the hospice has discovered since Towle and Sugar left in May. The first dog to replace Sugar did not work out very well. Towle suggests hospices choose dogs based on their disposition.

Springer spaniels, boxers, and Labradors are all good breeds to choose, she says. Hospice therapists or nurses could even experiment by trying out dogs from the local humane society to see which ones respond best to strangers, she suggests.

Some humane societies provide pet or puppy therapy for nursing home residents, and these animals might be ideal for hospice as well.

Once an agency selects the right dog, the key is to step out of the way and allow the dog to work its magic, Towle suggests.

"The key here was for me not to get in the way of the dog doing pet therapy," she explains. "I let the patient cue the dog and then let the dog respond to the patient's cues."

A pet therapy program requires a hospice's commitment and support from the top, because it does take some extra time to have a nurse or therapist bring the dog to patients' homes. The benefits can be so tremendous that Towle says she thinks every hospice should start a pet therapy program.

Asking the right questions

Sugar, for instance, helped a 10-year-old girl discuss how she felt about losing her grandfather, who was the only father figure she had ever known. "She sat down and was petting the dog, and it was then that she could say to me, 'What's going to happen when my grandpa dies?'" Towle asks.

Another time, Sugar had given one very frail older man the only playtime he had in his last days. Whenever Sugar visited, they'd play a game of his hiding doggie treats and Sugar nudging him to find them.

Finally it became apparent to the hospice staff that he was about to die, although he kept hanging on, waiting for someone. His son was supposed to arrive very soon, but the man kept asking for Sugar. Towle brought Sugar to him, and although he was very weak, he tried to play with her as he had before. Then he fell asleep and died that night.

"He didn't even wait for his son," Towle recalls. ■

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