

HOSPICE Management ADVISOR

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INSIDE

■ **Solving the nursing shortage:** An imaginative approach to recruiting and staffing flexibility are critical elements for attracting the staff you need. 123

■ **Meeting the needs of the black community:** A conference sponsored by the Congressional Black Caucus offers solutions to the problem of providing better hospice care to people who have distrusted the health care industry. 124

■ **Don't ignore the caregivers:** Full hospice care involves more than caring for patients; it also involves looking out for the caregivers. 127

■ **A day of uneasy anticipation:** A grief counselor in a hospice in the Washington, DC, area tells about the painful experience of confronting the anniversary of the terrorist attacks 129

NOVEMBER
2002

VOL. 7, NO. 11
(pages 121-132)

Nursing shortage brings rule switch: Contract nurses now meet requirement

Hospices must show diminished patient access and failed attempts to hire

Hospices that can prove they are forced to turn patients away because the current nursing shortage has left them without adequate staffing can now hire contract nurses to fill the gap without running afoul of Medicare regulations.

The Centers for Medicare & Medicaid Services (CMS) has issued a temporary measure that bends the core services requirement to allow hospices to contract for nursing services, rather than providing them directly as current regulations require.

The temporary measure will be in effect until Sept. 30, 2004, at which time CMS will re-evaluate the current nursing shortage to determine whether it should be extended.

The memo was issued on Sept. 12 by **Steven Pelovitz**, director of the survey and certification at the Center for Medicaid and State Operations. It came after the California Hospice and Palliative Care Association (CHAPCA) asked CMS to clarify the "extraordinary circumstances" clause in the core services provision, which describes the minimum services a hospice must directly provide its patients, such as nursing services. The provision includes language that allows hospices to bend the core services requirements. Specifically, CHAPCA sought guidance on whether the current nursing shortage can be considered "extraordinary circumstances."

"The regulations allow a hospice to use contracted staff, if necessary, to supplement hospice employees in order to meet the needs of patients during periods of peak patient loads or under extraordinary circumstances," the memo states. "If contracting is used, the hospice must maintain professional, financial, and administrative responsibility for services."

In short, CMS has granted a qualified exception to the requirement that calls for hospices to provide nursing services using its own employees.

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However, CMS' sympathy for the plight of hospices doesn't come without its share of red tape.

To qualify for the exemption to the core services provision, a hospice is required to provide written notification to its state survey agency when the nursing shortage has become so severe that the hospice is unable to hire its own nurses. In addition, the hospice must estimate the number of nurses it believes it will need to employ under contract. This notification should do the following:

- Give an estimate of the number of patients that the hospice has not been able to admit during the past three months due to the nursing shortage and the current and desired patient/nurse ratio for the agency.
- Provide evidence that the hospice has made a good-faith effort to hire and retain nurses, including:
 - copies of advertisements in local newspapers that demonstrate recruitment efforts;

- copies of reports of telephone contacts with potential hires, professional schools and organizations, recruiting services, etc.;

- evidence that salary and benefits are competitive for the area;

- evidence of any other recruiting activities (e.g., recruiting efforts at health fairs, educational institutions, health care facilities, and contacts with nurses at other providers in the area);

- an ongoing self-analysis of the hospice's trends in hiring and retaining qualified staff.

- Demonstrate that it has a training program in place to assure that contracted staff are trained in the hospice philosophy and the provision of palliative care prior to patient contact.

- Provide assurance that contracted staff are providing care that is consistent with the hospice philosophy and the patient's plan of care.

- Show that contracted nurses are used to supplement the hospice nurses employed directly. Contracted nurses should not be used solely to provide the continuous nursing level of care or on-call service.

- Show that the hospice is expected to continue its recruitment efforts during the period that it is contracting nurses.

"We commend the Department of Health and Human Services for being flexible and responsive to our concerns," says **Margaret Clausen**, CAE, executive director of CHAPCA, which is based in Sacramento.

Last year, CHAPCA asked CMS for clarification on contract nursing rules and gave the agency data from a survey of its membership. The survey showed that although 88% of California hospices had increased their salaries, nursing vacancy rates averaged 14% over a six-month period.

More telling, says Clausen, are the statistics on patient access to hospice. More than one-third of hospices surveyed reported having to turn patients away because they did not have the staff to handle the added caseload. That translated to between three and four patients per hospice who were placed on waiting lists each week.

The National Hospice and Palliative Care Organization (NHPCO) applauded CMS, as well. The temporary measure will help ensure access to hospice as the industry tries to find solutions to the long-term nursing shortage problem, says **Judi Lund Person**, MPH, vice president for state and regulatory affairs for NHPCO in Alexandria, VA.

The temporary solution will likely not have an

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. First-class postage paid at Atlanta, GA 30304. POSTMASTER: Send address changes to Hospice Management Advisor™, P.O. Box 740059, Atlanta, GA 30374.

Subscriber Information

Customer Service: (800) 688-2421 or fax (800) 284-3291, (customerservice@ahcpub.com) **Hours:** 8:30 a.m.-6 p.m. Monday-Thursday; 8:30 a.m.-4:30 p.m. Friday, EST.

Subscription rates: One year (12 issues), \$329. Outside U.S., add \$30 per year, total prepaid in U.S. funds. Two to nine additional copies, \$197 per year; 10 to 20 additional copies, \$132 per year. For more than 20 copies, call customer service free of charge when contacted within one month of the missing issue date. **Back issues**, when available, are \$55 each. (GST registration number R128870672.)

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Editorial Questions

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effect on hospices' nursing shortage. While contract workers will fill a void, the task of filling open hospice nursing positions with full-time employees will still be difficult due to stiff competition from hospitals, physician offices, and other settings where the pay is better and the work often is less demanding. While the health care industry and nursing associations are attempting to make fundamental changes to attract more nurses to the profession, Clausen sees the nursing shortage continuing beyond 2004, especially for hospices.

"I don't think the nursing shortage will be solved in two years," Clausen says. "What is being proposed are institutional changes, and institutional changes take time."

One example of institutional change that is already under way includes a group of more than 60 nursing organizations that released a broad strategic plan in April addressing the root causes of the growing nursing shortage.

"Nursing's Agenda for the Future" identified a number of domains in which nursing leaders envisioned change, along with a strategy to achieve their vision. The domains are: leadership and planning, economic value, delivery systems/nursing models, work environment, legislation/regulation/policy, public relations, communication, professional/nursing culture, education, recruitment/retention, and diversity.

The plan is as much an industry statement as it is a strategic tool. It offers a picture of where the nursing industry sees itself being by the year 2010. Rather than allow the current trend to continue where demand for nurses will exceed the supply by 2010, the industry hopes to set into motion changes that would make nursing more attractive and fulfilling.

While hospices use contract nurses, the supply of nurses will continue to work against them, making it important for hospices to continue their efforts to make hospice nursing attractive, particularly to new nursing school graduates and veterans who long to reconnect with hands-on nursing.

"[CMS' temporary measure] is not a reason to stop recruiting," says Lund.

Just how NHPCO thinks hospices should recruit nurses and retain current ones can be gleaned from its recent monograph, "Finding Answers to the Nursing Shortage." In it, the NHPCO advocates creative recruitment and retention efforts, as well as increasing salaries to become competitive with other providers. ■

Solving nursing shortage requires imagination

Quality-of-life issues a key point

With many hospices trying to fill open positions, it's easy to lose sight of the importance of keeping currently employed nurses from leaving. While nurse recruitment is important, remember that nurses who are already on staff are often seasoned hospice nurses. Their years of experience cannot be replaced by inexperienced nurses.

In 2000, Hospice Atlanta faced an employment crisis of its own. A significant number of nurses and social workers left, many to take jobs with other institutions — including competing hospices that paid higher salaries.

Pamela Melbourne, RN, MN, director of clinical services for Hospice Atlanta, says the hospice raised salaries to address its retention problems. That has made an impact on retention, Melbourne says. While she is unable to cite specific numbers, anecdotal evidence points to fewer nurses quitting for other opportunities.

Salary not final word

But salary is not the final word in retaining nurses. Salary combined with working conditions and quality-of-life issues will strengthen a hospice's standing with its staff. Strategies cited by the Alexandria, VA-based National Hospice and Palliative Care Organization (NHPCO) in its monograph "Finding Answers to the Nursing Shortage" include:

- giving nurses opportunities for professional development, including conferences and continuing education;
- encouraging and rewarding staff who seek professional certifications;
- investing more resources in new-hire orientation;
- adding benefits, such as child care, transportation, and wellness programs;
- giving nurses more participation in management decisions through quality improvement programs;
- supporting programs that address grief and loss issues among nurses.

The overall aim of retention strategies is not only to provide programs intended to boost job

satisfaction but also to gauge job satisfaction among nurses. Hospice Atlanta conducted an employee survey to determine what changes could be made to address staff concerns. Overwhelmingly, staff wanted a say in the direction of the organization, rather than having edicts handed down to them without their input.

Also, the hospice found that nurses wanted more predictable schedules. So rather than requiring nurses to take on-call shifts, Hospice Atlanta hired nurses whose specific job responsibility would be to handle after-hours and weekend calls.

Focus recruitment on job satisfaction

The reality, however, is that nurses will quit, retire, or move on no matter what you do. Hospices need to develop a strategy that attracts experienced nurses and develop training programs to train young nurses or nurses coming from other disciplines.

Experts agree that the two areas in which hospices should focus their recruiting attempts are:

- high job satisfaction as a result of practicing hands-on medical care and the close relationship nurses develop with their patients and families;
- flexible working hours that will attract nurses who can't work traditional 40-hour weeks.

Job satisfaction is perhaps hospice's greatest selling point, says the NHPCO.

Knowing that competition for hospice nurses is fierce, hospices may be compelled to broaden their pool of prospective nurses by not limiting their search to nurses with hospice experience.

For prospective nurses outside of hospice, the message of greater job satisfaction may have greater impact. Hospices can make use of those nurses' current job dissatisfaction. Hospices should stress how hospice nurses can have a direct and immediate impact on patients and their families and recount the gratitude families have for hospice workers who helped them get through a difficult situation.

Still, money is a strong motivating factor. To help neutralize the money factor, providing employment that enhances quality of life beyond professional job satisfaction can go a long way toward persuading a nurse to join a hospice.

The NHPCO advocates offering prospective employees flexible hours and working arrangements. Some hospices, for example, allow nurses to work as many hours as they like, whether it's 20 hours a week or 40 hours a week. This allows

talented nurses, who, for example, cannot work a full-time job because of family commitments, to maintain the balance between work and family that is valued by workers.

Still, with no end to the nursing shortage in sight and growing competition for both experienced nurses and recent nursing school graduates, hospices may be faced with having to redefine the responsibilities of not only registered nurses but licensed practical nurses (LPNs) as well. According to the NHPCO, one solution might be to expand the role of the more abundant LPNs and use RNs as case managers.

In addition, hospices will need to explore how technology can help improve efficiency and lower the demand for nurses. ■

Blacks in Congress focus on end-of-life care

Better care for African-Americans addressed

Like a wave that is born thousands of miles from the nearest beach, the movement to improve end-of-life care for African-Americans seems to be gathering strength as it bears down on the health care landscape.

In September, the Congressional Black Caucus (CBC) took up the mantle of improving end-of-life care for African-Americans by hosting a legislative conference dedicated to the issue. It marked the emergence of end-of-life care for African-Americans as an issue worthy of political and social discussion outside the realm of health care industry circles.

Organizations such as the Institute of Medicine, the Robert Wood Johnson Foundation, The National Institutes of Health, and the National Hospice and Palliative Care Organization have all acknowledged the disparity in palliative care between minorities and whites. Yet, the debate over what should be done has rarely carried over into mainstream society.

"This is the largest group of African-Americans I have seen talking about death and dying," says **Bernice Harper**, PhD, MSW, MSC.PH, medical care advisor for the Centers for Medicare & Medicaid Services (CMS) in Baltimore and a panelist at the CBC meeting.

Harper and the rest of the panel of experts in end-of-life care discussed reasons why African-Americans should be concerned with the disparity in the quality of palliative care, why barriers exist, and what should be done to level the playing field.

Questioned about whether palliative care is an important issue, given all the other disparities African-Americans face, **Richard Payne**, MD, chief of the pain and palliative care service at Memorial Sloan-Kettering Cancer-Center in New York, told attendees that improving palliative care is an important

issue because it directly affects the quality of health care African-Americans receive from a system that it has mistrusted for decades.

He used the example of a minority woman diagnosed with metastatic cancer and HIV/AIDS whom he recently treated. This single mother of two children was cared for by her own elderly mother, who was overwhelmed by her caregiver responsibilities.

“She needs a doctor who can treat pain, knows how to treat fatigue and depression, is a good communicator, can help her communicate with her family, and can reach out to help her get the spiritual care she needs,” said Payne. “These are the kinds of things that get done in palliative care, and it needs to be done in the context of treating her AIDS and treating her cancer. This is part of the other disparity issue. There are people in this country who get this good care. I think everyone should get this good care.”

“There are disparities. We have to talk about getting people better access, but we also have to talk about the quality of care of the system they are accessing.”

Mistrust fuels disparity

But getting the kind of care that Payne describes is often difficult for African-Americans because of disparities that occur well before patients reach the end of their lives. Mistrust of the health care system has been nurtured by historical landmarks such as the 1930s Tuskegee study in which black men with syphilis were denied penicillin, and by personal experiences and perceptions.

For example, African-Americans are among the largest population without health insurance. So, even when elderly dying African-Americans are told that hospice care is covered under Medicare, they are wary of the benefit after a lifetime of being denied coverage for other medical conditions.

“We don’t give them health insurance, and then we tell them that when they are ready to die, ‘We have insurance for you,’” says **Henrie M. Treadwell**, PhD, health program director for the W.K. Kellogg Foundation in Battle Creek, MI.

“People don’t want to give their trust to a system that hasn’t had their best interest in mind.”

Distrust, however is only a part of the equation that leads to disparity in end-of-life care. Barriers to good end-of-life care include lack of education among physicians, particularly in pain management; fear of addiction to pain medication by minority patients; and even

faith issues, says **Beny J. Primm**, MD, executive director of the Addiction Research and Treatment Corp. in New York City.

The combination of all these things results in delayed access to palliative care, says Primm. “We get to the doctor a little late,” he adds. “We get accustomed to a certain amount of pain. We need to get to the doctor a lot earlier.”

Bridging the gap between good and bad end-of-life care requires both education and understanding from all those involved in the dying process — insurers, physicians, patients, and their families.

Risa Lavizzo-Mourey, MD, MBA, senior vice president and director of the Health Care Group of the Robert Wood Johnson Foundation in Princeton, NJ, suggested a three-pronged approach to equalizing access and quality of care:

- Teach professionals how to provide good palliative care.
 - Provide an environment that is hospitable to palliative care.
 - Educate the community about palliative care.
- “A cultural perspective is complex,” Lavizzo-Mourey says. “We know good palliative care depends on a sense of spirituality, good medicine, policy, and interaction between the health care professional. We all bring a cultural bias to those interactions. What makes care culturally sensitive is that people understood that dynamic.”

“We don’t give them health insurance, and then we tell them that when they are ready to die, ‘We have insurance for you.’ People don’t want to give their trust to a system that hasn’t had their best interest in mind.”

In past issues of *Hospice Management Advisor*, experts in improving end-of-life care for African-Americans advised hospices to address the following concerns in order to reach African-Americans successfully:

- Make your hospice a model of the community.
- Show respect for African-Americans' cultural heritage and leadership in the community.
- Address unique spiritual needs.
- Take advantage of strong community ties.
- Enlist the help of those in the community.

Hospices should ensure that those treating the community are a fair representation of the community itself. If the community has a significant African-American population, then a significant portion of your staff should likewise be African-American. Caring about diversity in an organization is a big first step toward showing minorities in a community that their interests are important.

But that is only the beginning. Hospices cannot simply rely upon sending their own representatives, such as a nurse or social worker, into a community to provide hospice education. Even though a hospice is sensitive to a community's need to see someone of similar racial background, that gesture doesn't go far enough.

There may still be a belief that the hospice representative is speaking to benefit the organization he or she represents, not to serve the best interest of community members. For that reason, public awareness programs in African-American communities have limited value.

Listen more than you talk

But those same kinds of programs implemented in conjunction with community leaders, such as ministers and civic leaders, have a greater impact. Further, hospices must be willing to listen more than they talk.

Spiritual care is a good example. While hospices are generally open to providing a wide variety of spiritual care through their own spiritual counseling, African-Americans have a rich spiritual heritage that is deeply rooted in community worship.

Many African-Americans resent some hospices' notion that they can come into a black community and provide spiritual care. Still, addressing African-American communities' spiritual needs should be a priority. But hospices have to address African-Americans' spiritual needs in a more cautious manner, creating a network of local ministers and other religious leaders who will provide

the bulk of spiritual care. People are more likely to listen to their minister because the church has always been the cornerstone of the African-American community.

As hospices become more open to suggestions from those they are trying to serve, they will gain a greater understanding of the challenges that African-Americans face when confronted with a terminal illness. The differences in various approaches to dealing with death and caregiving will become clear.

Understanding family dynamics

For example, the way African-American families care for their dying loved ones differs from the way white family members do. One study found the following:

- African-American females accounted for 86% of that group's caregivers, while 74% of whites were caregivers.
- African-American men made up 14% of that group's caregivers, while 26% of white men were caregivers.
- African-American daughters made up 42% of that population's primary caregivers, while white daughters made up 27% of caregivers.
- African-American patients relied twice as much on secondary family caregivers for assistance with caregiving tasks. Specifically, 58% relied on secondary helpers for assistance with intimate care tasks (e.g., bathing), 71% relied on secondary helpers for mobility care tasks (e.g., walking), and 62% relied on secondary helpers for assistance with housework tasks (e.g., cooking, cleaning).

For hospices, findings such as these could mean the following:

- Families should be informed and counseled on the availability of services to assist with care in their communities.
- Health care professionals should monitor patients' and caregivers' need for services throughout the illness trajectory.
- Community groups and agencies should focus on supplying support to African-American female caregivers (particularly daughters), as a much larger percentage of women provide care in African-American families than in Caucasian families.

Because of the heavy involvement of African-American women in providing care, design classes, support programs, and booklets specifically to meet their needs.

In the end, African-Americans and other minorities need to be educated about hospice itself. Many minorities misunderstand what hospice entails. For example, some believe that hospice is a place where the sick are sent to die, rather than a service that allows people to die at home among family and friends. In fact, upon learning what hospice is all about, many will find it to be familiar.

“People of color have been caring for their own since the beginning of time,” says Harper. “They cared for the dying in their homes. Back then we didn’t call it hospice. Now we are going to care for you, provide services, and make you comfortable. Your family members are going to care for you, but we want you to have these extra services. We don’t want you wracked with pain. We want you to have all the comforts. You may have your family with you, but you need a social worker, nurse’s aide, and a physician, and we’ll provide these to you.” ■

Full hospice care means meeting caregivers’ needs

Training will boost their confidence

Caring for the dying is an enormous responsibility. No one knows this more than the nurses, social workers, and chaplains who do it day in and day out as hospice workers. The presence of these hospice workers in the home is a welcomed respite for loved ones who must provide the bulk of the care.

But what happens in between visits? Often, the caregiver is left feeling isolated and overwhelmed. One way to ensure quality care in the absence of staff is to teach loved ones how to be better caregivers.

“The No. 1 priority is safety: Is the patient safe?” says **Elizabeth Pitorak**, MSN, APRN, CHPM, director of the Hospice Institute at the Hospice of the Western Reserve in Cleveland. “The assessment will play a key role in determining the kind of training the caregiver should receive.”

Given that family members play such a pivotal role in caring for the dying patient, hospice staff need to attend to the needs of the caregiver as well to the needs of the patient. Attention needs to be paid to not only teaching caregivers the

mechanics of caring for a loved one — how to give a bed bath or monitor instruments, for example — but also to help caregivers recognize their own needs and limitations.

According to Pitorak, staff should focus on the following areas to help family members become better caregivers:

- physical concerns;
- emotional needs;
- role and relationship of caregiver in the family structure;
- spiritual concerns;
- understanding of the dying process.

One of the major themes of hospice care is pain management. A focus on palliative care will do much to improve the quality of the remaining days of a patient’s life. While hospice workers understand this philosophy, family members and caregivers may not. They often are reluctant to administer pain medication out of fear of overdosing the patient or contributing to addiction.

Hospice staff need to help caregivers understand that pain is a reality in their loved one’s life and that pain medication is designed to improve the quality of the life that remains, Pitorak says. Further, staff must stress the importance of keeping up with scheduled medication to avoid causing the patient undue pain. As staff train caregivers in how to administer the medication, they should tell caregivers about the side effects of the medications being used to avoid surprises that could result in noncompliance or misuse.

“The object is to take the fear out by giving them the knowledge they need to feel confident,” Pitorak says.

Staff also must be aware of physical concerns relating to the caregiver. A common concern is whether the caregiver is getting enough rest due to the round-the-clock duties of caring for the patient and tending to household responsibilities. It is often easy to focus primarily on the patient and miss the warning signs of a caregiver in need of care.

The best way to keep on top of caregivers’ needs is to establish a rapport with them, keep lines of communication open, and show concern for both the patient and the caregiver.

One of the roles a caregiver has is to help a loved one accept that he or she has a terminal illness. Patients often deny they are sick and avoid necessary treatments — medical or otherwise — that negatively impact their quality of life.

A caregiver must also be able to encourage the

patient to share his or her feelings about the situation, including fears about leaving loved ones behind. To do so, caregivers must be able to discern the proper times to elicit open conversation and avoid communicating through heated arguments.

As patients are faced with their mortality, they begin to inventory life's unfinished business, activities they have always wanted to do, or broken relationships they have long wanted to mend. Caregivers should play a major role in improving their loved one's life by helping tie up these loose ends.

But caregivers cannot attend to the above tasks if they are not on a solid emotional foundation themselves. So, in order to empower caregivers to be supportive and attentive to the needs of the patient, hospice staff need to attend to the emotional needs of the caregiver.

This begins by assessing the caregiver's ability to cope, says Pitorak. It is common for the caregiver's coping abilities to be impaired by the knowledge of a loved one's terminal illness. Staff should assess the caregiver's knowledge of the disease. The ensuing discussion will likely yield insight into the caregiver's fears and expectations and offer signs of anxiety and depression that must be dealt with.

"Help them cope. Empower them by helping them re-identify coping mechanisms," Pitorak says.

Roles and relationships

Emotional needs are affected in part by the roles and relationships caregivers and patients play in the family structure both before and after the diagnosis. For example, what seems like denial may be the patient's attempt to protect loved ones from what is really happening. The caregiver needs to be able to reassure the patient that the caregiver is willing to discuss all aspects of the illness, no matter how difficult it may be for both parties. This should help the patient get past this form of protection and allow the patient to prepare for his or her own death, says Pitorak.

What often triggers fear and anxiety among dying patients is the thought of leaving behind a spouse or family that is unprepared to carry on after the patient dies. An elderly man who handled the family finances could fear that his wife will founder financially. Or an elderly woman who prepared all the family meals may be concerned that her husband won't eat with no one to cook for him.

For both sides to be at peace, there needs to be a dialogue between the patient and caregiver, and this can be facilitated by hospice staff. Both the caregiver and the patient need to be able to tell each other what their fears are.

If, for example, the issue is self-sufficiency of the survivor, then the hospice staff should help both sides address their concerns. If the wife fears her husband will not be able to prepare his own meals, the hospice worker should work with the husband to devise a plan that will improve his cooking skills, which should be demonstrated to his wife.

"In order for the patient to have peace, you have to teach the caregiver to be self-sufficient. Encourage the caregiver to care for themselves," says Pitorak.

Professional caregivers must also help family caregivers work through important family issues. Patients and caregivers, for example, may disagree on issues such as when and how to share their feelings.

Hospice workers can help facilitate the resolution of outstanding issues in these ways:

Tell caregivers their needs matter

- **Get caregivers to explain their needs openly.**

Caregivers need to be taught that their feelings and needs matter and that they should feel that they can ask the patient to do something that will make their lives easier or their caregiving responsibilities more manageable. For example, it is not unreasonable for a caregiver to ask a loved one to give notice when any pain arises, rather than waiting until it becomes so severe that it creates a conflict between caregiver and patient.

Teach caregivers that conflict resolution does not always mean everybody is happy. Remind them that conflicts are resolved through compromise, a fact they may have forgotten under the strain of dealing with a terminal illness.

- **Stress to caregivers that the patient should make as many of his or her decisions as possible.**

A good example of letting a patient make his or her own decisions is when adult children living some distance away from the patient want to move him or her into a nursing home. Although a move to a nursing home may make the adult children feel at ease, it may not be what the patient wants. If the patient understands the consequences of his or her decision to remain at home, including the absence of a caregiver at home, the children should

accept the patient's right to make that decision. Family members need to be told that taking away their loved one's ability to make decisions can undermine his or her feelings of control, which can interfere with the person's ability to deal with other aspects of his or her illness.

Spiritual concerns

Another source of conflict can be unmet spiritual needs. Patients are not always forthcoming about their questions of faith or place in the universe. Hospice workers are trained to get patients to express their spiritual needs, but often it is the caregiver who prompts the discussion that leads to the patient seeking a hospice chaplain or their own clergy.

The first step in meeting patients' spiritual needs is training caregivers on what spirituality is, given its very broad definition. In some cases, the caregiver may be deeply religious, while the patient is not. Hospice workers need to train family caregivers about what spiritual care actually is, including that it does not necessarily involve religion.

Teach caregivers to share not just their faith with their loved ones, but their uncertainties, as well. This will help them understand their own relationship with those around them and a higher being, and they may reconnect with beliefs they held before their illness, Pitorak says.

Teach the caregiver that listening is the most important thing the caregiver can do to help, including letting the patient know that he or she is willing to discuss spiritual matters when the patient is ready. Help caregivers understand their limitations. If the caregiver finds it difficult to listen to the patient's concerns, then the caregiver needs to be able to call the hospice chaplain or the patient's own clergy to help the patient work through spiritual concerns.

Hospice workers need to be concerned about the spiritual needs of the caregiver, as well. Caring for a loved one who is dying often brings up very difficult issues, including questions about fairness, fear about the future, and other universal questions.

Just as the caregiver tries being available, so too should hospice workers. While this is not a new concept, Pitorak says it is easy to forget about the needs of the caregiver. And if the caregiver's needs aren't addressed, the caregiver will have difficulty helping the loved one sort through his or her spiritual concerns. ■



Sept. 11, 2002: A grief counselor's perspective

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But for a lively wind rustling countless flags, Sept. 11, 2002, dawned in much the same fashion as it did a year ago — another gentle late-summer morning. For months, a heightened media focus on this first anniversary and the nightly drone of military planes created an atmosphere of apprehension bordering on dread here in the Washington, DC, area. As a hospice grief counselor whose personal and professional life has been intertwined with the events of the past 12 months, this was a day of uneasy anticipation.

Like all my colleagues in hospice everywhere, I was aware that 9/11/02 would not be the conclusion of suffering. I worried that those who had hoped for an ending might be devastated by the harsh reality of continued sorrow. For my clients who lost family members a year ago, this would be yet another painful reminder that someone they loved would not be walking through the front door at 6:30 p.m. For the bereaved whose loved ones died in hospice or through other circumstances, this was yet another difficult time where the magnitude of their loss would go unacknowledged.

In the days since 9/11/01, I have been walking a fine line of political correctness in honoring the families of 9/11 victims while also reminding the media and audiences of ordinary people that every loss is important. This was my mission in the days leading up to Sept. 11, 2002. With my bereaved clients, some of whom would be gathering at the Pentagon, we had begun planning for this day since the six-month anniversary in March. We had considered the challenges of deriving meaning and/or locating refuge during one more very public commemoration of their private grief.

Over the past year, the hospice organization where I work, The Hospices of the National Capital Region, has focused on all who grieve,

and had once again extended its safety net of support to the entire community. The Hospices held a service of dedication on Sept. 8 honoring the courage of all who mourn. Comforted by the delicate plucking of a harp on the grounds of our inpatient unit, over 50 people assembled to have their losses and grief recognized.

We expanded the operation of our toll-free help line to 24 hours a day from Sept. 9 through Sept. 15. My “shift” was the evening and nighttime hours. Our Public Engagement department scheduled television and radio interviews on Sept. 10 and 12th for me to share our message and publicize our free services.

At 6:45 a.m. on the anniversary, I drove past the Pentagon on my way to a speaking engagement on grief for the medical staff of a veterans’ retirement home. I listened to the radio, alert to the possibility of danger on this day. My gas tank was full and I was wearing relatively comfortable clothing “just in case.” My family had been reminded the night before that in the event of an attack on Washington, we would all meet at my son’s apartment in southwestern Virginia.

‘Where were you on Sept. 11?’

The 75-minute talk with the medical staff included observance of a moment of silence for the 9/11 heroes and victims, but also focused on the many losses the staff had experienced over the past year. Acknowledging our community grief, the participants agreed that the question of “Where were you on Sept. 11, 2001?” had gained equal importance — for those of us old enough to remember — to the same question asked of President Kennedy’s death in 1963.

Before I left the building, a staff member asked me to phone her daughter who was grieving the death of someone special on Flight 93. I validated this young woman’s choice to call in sick as her means of self-care on this difficult day and felt buoyed in return by her openness to me, a stranger.

My emotions were running high as I later waited in vain to be interviewed by phone for a live radio network broadcast. I was semi-relieved that my “expertise” was not needed. The next “event” was a local county’s ceremony honoring its residents who died on Sept. 11. I stood in the sun and listened to one of my clients speak eloquently of the redemptive lessons of tragedy that often result in honorable deeds both grand and humble.

Finally, it was time for me to begin contemplating the enormity of the events of the day and the year. While empathizing with the pain my client expressed, I also celebrated her courage in taking a risk to share her private feelings in this public forum. For the rest of the day, I reflected on the many privileges afforded by my years of working in hospice: the intimacy of sharing the moment of a loved one’s last breath; the respect for the protracted and individual nature of grief; and the gift of wisdom and compassion shown by this lovely young woman and others evident even in the darkest hours.

I ended the day and began the next waiting for the Help Line to ring; it didn’t. During the long, quiet hours, I flipped television channels to find my own refuge from the very public reminders of this painful anniversary. Sept. 12 was back to business as usual. The difference for those of us working in hospice is that we must put the tragedy of 9/11/01 in the context of all the other pain, suffering, healing, and joy that we experience on a daily basis. Long after the majority of people have moved on from 9/11, we will still remember and we will be there for those who need our support. ■

News From the End of Life

Electronic filing proposed for CMS cost reports

Delay or waiver may be possible

Hospices that file their next cost report on or after Dec. 31 will have to do so through electronic submission using a standardized electronic format, according to a recent Centers for Medicare & Medicaid Services (CMS) proposal. The proposed rule would amend current cost report requirements for all hospices, organ procurement organizations, rural health clinics, federally qualified health centers, community mental health centers, and end-stage renal disease facilities.

Hospices that can prove a financial hardship due to the proposed rule would be allowed to delay implementation or could be granted a

waiver. Despite the hardship, Medicare officials contend the new rule would allow for more accurate preparation and more efficient processing of cost reports.

In the July 26 issue of the *Federal Register*, CMS stated that for the first two years of the rule, a hard copy of the cost report would be submitted with the electronic version. The agency said that the electronic cost reports “will virtually eliminate computational errors and substantially reduce preparation time. Moreover, the use of cost reporting software will save time whenever the provider needs to change individual entries in a cost report.”

Hospices and other groups affected by the change may submit a written request for a waiver or a delay of these requirements based on financial hardship. CMS also will allow providers with low or no Medicare utilization to request a waiver of electronic cost reporting. ▼

Article examines palliative care, pain management

Use of sedation, other ethical issues addressed

In its July 2002 issue, the *American Journal of Nursing* examines the difficulty in managing pain in terminally ill patients and the role nurses can play in alleviating their patients’ pain as their patients face the end of life.

The article is the second in a bimonthly continuing education series on palliative nursing care, funded in part by a grant from The Robert Wood Johnson Foundation. The article addresses several areas of pain management, including: pain assessment, the principles governing the use of analgesics, nonverbal cues that may indicate pain, differentiating pain from other symptoms, the use of sedation, and related ethical issues.

The article, “Difficulties in Managing Pain at the End of Life,” can be accessed on line at www.aacn.nche.edu/elnc/ajnl.htm.

For most terminally ill patients, pain relief is possible. Yet pain remains a primary concern for many patients and their families. Despite decades of efforts to improve pain management, researchers continue to document inadequate assessment of pain and unrelieved pain in patients with a number of life-limiting diseases.

The *American Journal of Nursing* article presents methods nurses can employ to help manage patients’ pain, including careful assessment of nonverbal cues when the patient is not verbal, the administration of pharmacologic and non-pharmacologic treatments, and sedation when necessary to provide comfort.

The author of the article, **Joan T. Panke, MA, RN, APRN**, is a palliative care nurse practitioner and is the executive director of the DC Partnership to Improve End-of-Life Care in Washington, DC. She also is a curriculum consultant and faculty and advisory board member on the End-of-Life Nursing Education Consortium project. ▼

Grants intended to boost geriatric nursing education

Separate programs promote care for the aging

The ramifications of an aging nursing faculty plus a nursing turnover rate of almost 26% are particularly serious for geriatric care, says **Linda Hollinger-Smith, PhD**, director of research at the Mather Institute on Aging in Evanston, IL. But the Learn, Empower, Achieve and Produce (LEAP) staff development program Hollinger-Smith started has reduced her facility’s turnover rate from 76% to 34% for certified nursing assistants and from 47% to 22% for RNs.

LEAP, begun as an initiative to help RNs in long-term care, is funded by a grant from the Health Resources and Service Administration. Mather LifeWays is using the funds in collaboration with nursing schools at three major universities to offer a web-based distance-learning

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program that gives nursing faculty in 26 states the latest geriatric nursing information.

The program consists of six on-line courses of eight weeks each that students may take at their own pace and can complete in about a year. Rush University in Chicago, Yale University in New Haven, CT, and the University of Wisconsin - Milwaukee are partnering with Mather on the program, which allows nursing faculty to enter at any time during the three-year grant period.

Hollinger-Smith says she started LEAP in 1999 to help RNs, certified nursing assistants (CNAs), and practical nurses develop and remain in their health care careers. The program focuses on the so-called "soft skills" like learning how to communicate, developing positive relationships with supervisors and co-workers, and learning how to recognize and reward good behavior.

Hollinger-Smith says her program succeeds by building a "career ladder" that offers CNAs financial incentives for increasing their skills in specialized areas such as skin care or dementia care, for example.

One of the key elements of retention, Hollinger-Smith says, is providing a thorough orientation that makes new health care workers feel welcome in their workplace and encourages them to become mentors for those hired after them. "We're focusing on this instead of on recruitment because all of the literature says there are not enough people in the wings waiting to enter the work force," explains Hollinger-Smith. She points out that over the next seven years there will be one million new positions for CNAs, but according to the Bureau of Labor Statistics, only about 400,000 women will be available to choose that career path. "Even if every one of them went into the direct care work force, there just aren't enough people," Hollinger-Smith says. "We really have to focus on how we can better develop and retain the folks we have now."

ANA gets \$5 million aging-care grant

The American Nurses Association (ANA) has also received \$5 million to improve nursing skills for the aging through a five-year grant, "Enhancing Geriatric Competence of Specialty Nurses," that seeks to help more than 400,000 nurses deliver better care to aging adults.

The ANA will work with specialty nursing organizations to implement the grant, which has three goals:

- creating permanent structures for geriatric activities in specialty nursing associations;

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- promoting gerontological certification of specialty nurses;
- developing a Web-based comprehensive geriatric nursing resource center.

Virtually all nurses provide care to older adults at some point in their careers. Current demographics project that the over-65 population will double over the next 30 years, reaching 70 million by 2030. Those over age 85 are the fastest-growing segment of this population, which makes by far the biggest demand on health care services and facilities.

The grant is funded by the Atlantic Philanthropies and implemented through a strategic alliance between ANA and the Hartford Institute for Geriatric Nursing. ■

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