

HOSPICE Management ADVISOR™

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Alzheimer's patients face an uphill battle to obtain hospice care

Caregivers 'digging deeper' to solve problems

Few manifestations of human frailty are more terrifying than Alzheimer's disease, with its progressive decline of all aspects of the patient's cognitive function and personality. The needs of Alzheimer's patients for care and symptom management, and the needs of their family caregivers for education and support, are immense. And the magnitude of the suffering is growing. An estimated four million Americans are currently afflicted by the disease, with that number expected to more than double in the next four decades, according to the Alzheimer's Association in Chicago.

Hospice's role in addressing this national tragedy can be problematic because of the difficulty in identifying a clear terminal phase of six months or less to live — and increasing insistence by government regulators that providers must meet this basic requirement of hospice coverage. In addition, some hospices have questioned what they can bring to the care of patients who are no longer able to communicate.

Recent issues of *Hospice Management Advisor* have highlighted the industry's struggles with the six-months-or-less requirement, and the desire by some in the industry to see it changed. However, published guidelines and new research can help sharpen providers' ability to make reasonable six-month determinations for many Alzheimer's patients.

Hospices strive to provide Alzheimer's care

Can hospices play a larger role in Alzheimer's care? How do hospices determine when an Alzheimer's patient is appropriately end-stage, with a clear prognosis of six months or less to live? And what can hospices offer to enhance quality of life for these patients, who often are uncommunicative or unresponsive? This month's cover story and related articles explore hospice and Alzheimer's from a number of perspectives.

The real question is whether hospices are willing to use the guidelines and fight for hospice access for these patients. (See article on making six-month determinations for Alzheimer's patients, p. 132.)

Alzheimer's is terminal

Alzheimer's is a terminal disease. There is no way to cure or reverse the progression of its destruction of the brain, called dementia. There are two drugs approved by the U.S. Food and Drug Administration for treating it, tacrine and donepezil hydrochloride, but these only postpone the inevitable. Alzheimer's patients become bed-bound in an average of eight years, requiring full-time care and assistance with all activities of daily living. By that point their family caregivers may be financially devastated, emotionally and physically exhausted, and at risk for serious health problems of their own.

Different databases indicate the proportion of hospice caseloads devoted to Alzheimer's patients is somewhere between 1% and 3%, although this figure does not reflect the greater number of patients with other terminal diagnoses who have dementia as a secondary or comorbid condition.

"Alzheimer's societies and advocates have been very vocal about their desire to see appropriate patients in hospice. They see that hospice is of great benefit," says **Stephen Connor**, PhD, vice president for research and professional development with the National Hospice Organization (NHO) in Arlington, VA. Hospices, by contrast, have been somewhat more reluctant partners, he observes.

Katie Maslow, MSW, Washington, DC-based director of the Alzheimer's Association's Initiative on Alzheimer's and Managed Care, sees a change in attitude toward hospice's role over the past year, "from 'This isn't going to work' to 'Let's figure out a way to make it work.'" Two workshop sessions at this year's recent Alzheimer's national education conference in Indianapolis directly addressed hospice's role, while others explored quality-of-life issues such as music therapy, healing touch, aromatherapy, spiritual concerns, and even reminiscing as a therapeutic intervention. The challenge, Maslow says, lies in identifying best practices in end-of-life care and finding effective models of collaboration between hospice programs and local Alzheimer's Association chapters.

"Alzheimer's patients, more than most other disease categories, are seriously underserved,

with very few resources. Families commonly go nuts — and bankrupt," observes **Brad Stuart**, MD, hospice medical director for Home Hospice, a program of VNA and Hospice of Northern California in Emeryville. "But hospices need to be careful because lots of resources are necessary, and the hospice team may need to be augmented with other resources," such as grant funding for supplemental attendant care.

"Hospice is not the full answer to Alzheimer's; it can't be. But there is a role for hospice, particularly in institutions such as skilled nursing or board-and-care facilities, where pain is severely undertreated," Stuart says. "When you hear patients howling day and night, for a certain proportion it's from pain. You need to sort that out and treat the pain. Pain assessment is something hospice has a lot of experience in."

When pain is treated properly, the aggressive behavior common to many Alzheimer's patients often declines, adds **June Dahl**, PhD, professor of pharmacology at the University of Wisconsin-Madison.

End-stage Alzheimer's actually presents a whole complex of symptom management challenges, notes **Mary Labyak**, MSW, LCSW, CEO of Hospice of the Florida Suncoast, Largo. "Those symptoms are coming to resemble the illness of advanced aging in general. Three percent of our patients have Alzheimer's as their primary admitting diagnosis, but we speculate that probably a quarter of our patients have Alzheimer's or other dementias of advanced aging."

What is hospice's value for Alzheimer's?

While many in hospice view the challenge of identifying a terminal phase of six months or less as the primary barrier to a greater role for hospice, others question what hospice can bring to the care of Alzheimer's patients — particularly those residing in nursing homes, where their basic care needs are likely to be met by nursing home staff. End-stage Alzheimer's patients lack the mental capacity to consent to hospice care and generally even the ability to say when they are in pain. Thus, hospice's customary goal for a self-determined life closure is not possible.

"One thing people need to think about: Is hospice a real choice for families, or just a way of tapping into a reimbursement stream?" suggests **Joanne Lynn**, MD, director of the Center to Improve Care of the Dying in Washington, DC, and founder of the MediCaring demonstration

project. “If it is a real choice, how do you articulate that choice?” she wonders. “My advice is that if you are in a hospice setting that could possibly maintain a major service array for Alzheimer’s disease, then go after those categories of patients that look like you could admit them, and learn how to take care of them,” Lynn says.

“Become more data-driven,” she urges. “Get to know your local PACE [Program of All-Inclusive Care to the Elderly] provider and the nursing homes in your community. See yourself as part of an overall array of Alzheimer’s services, and be thoughtful about how families are encouraged to use that array. Hospices could convene these conversations in their communities and encourage thoughtful decisions about which patients are appropriate for hospice,” Lynn says. “It’s unlikely that hospice would take over the Alzheimer’s continuum, but you need to be a regular player in the service array.”

Clarify goals of treatment

“The goals of treatment for these patients are frequently hazy,” Stuart observes. “Too often, nobody sits down and thinks: Is the goal to keep them alive as long as possible, or comfortable as much as possible? If we were clear on the goals of treatment, we could keep many more Alzheimer’s patients in the skilled nursing facility and not have to transfer them to the hospital at the end. They wouldn’t have to be intubated or treated with antibiotics, but instead would be given appropriate end-of-life care,” he explains.

Highlights of such an approach include “excellent symptom control — with confusion and agitation controlled with psychosocial support and medications — and, of course, their pain managed,” Stuart says. “The patient needs physical touch and contact, and emotional contact from family members. Insomnia and crying out at night can be controlled with medications. This kind of care also means excellent goal setting — trying to keep the patient as comfortable as possible and responding to problems as they come up — as well as educating and supporting the family so they understand that excellent end-of-life care is the right approach to take.”

Ladislav Volicer, MD, PhD, clinical researcher in the Geriatric Research Education Clinical Center at E.N. Rogers VA Medical Center in Bedford, MA, has studied end-stage Alzheimer’s patients extensively and determined that antibiotics for recurrent infections in end-stage Alzheimer’s patients

do not extend their survival and actually can increase their discomfort. However, psychiatric conditions such as depression may require pharmacological management, he says.

Lee Paton, RN, MS, a doctoral candidate in gerontological nursing at Oregon Health Sciences University in Portland has developed a program for the Alzheimer’s Association Portland chapter, aimed at educating family caregivers about the physical manifestations of end-stage Alzheimer’s disease. Threshold issues for families center on decision-making around IV antibiotics, tube feeding, and IV hydration. Families have a desperate need for information if they are to make appropriate decisions, but the information they need is more than just physiology, Paton explains.

“Families are often called into medical conferences where the focus is on the physician or nurse trying to change their minds about care. I find families usually have completely different questions,” Paton says. “How do you find out what are the real gut-wrenching issues for them?” Families also need someone to explain what’s happening as the patient is actively dying, a responsibility for which hospice is uniquely qualified.

“Even the most confused people respond to human touch, human presence,” adds Labyak. “We can’t discount our ability to have a therapeutic effect” through interventions aimed at creating a more comforting milieu or environment, she says. Music, color, and aromatherapies are examples of the kinds of things that can help these patients become less agitated or have less pain, she adds. “You also have a population of caregivers who go on to have medical complications of their own, and who could really use the support of hospice.”

Even in the nursing home setting, hospice can be an important addition to the Alzheimer’s resident’s quality of life, says **J. Donald Schumacher**, PsyD, CEO of Hospice Association of Western New York in Cheektowaga. “Generally, you can identify physical care that may be appropriate. Even though these patients are not cognizant, they can express real pain when they feel it and real unhappiness when unhappy,” Schumacher says. “As a clinical psychologist, I would recommend erring in favor of helping them rather than not helping.”

Alzheimer’s care can be a challenge for hospice professionals, observes **Paul Brenner**, MDiv, coordinator of Jacob Perlow Hospice in New York City. “The usual ways of getting rewards from

their work involve in-depth emotional exchanges with their patients. With Alzheimer's, that isn't going to happen. So it means digging deeper into our own characters to find where the human connection might be," he explains.

"Regardless of what they cannot do or say for themselves, they aren't vegetables; they are still people," Brenner says. "Getting families to tell stories of what the person was like pre-Alzheimer's is one way for hospice workers to start to make that connection. Anything hospice can do, such as music therapy, that can bring back some glimpse of who that person was, absolutely alters how the family views this time. Because the patient can't communicate it in words, the only way to do this is to look for changes in affect or body language," he relates.

"It's not uncommon for the patient to have crawled into a fetal position, moaning and groaning, crying out when touched. If these things lessen through hospice's intervention, that is an indication that quality of life improvement has taken place. But it falls to hospice to find ways to define who this person is, rather than have him or her be 'thinged' into something less than human." Such an approach should have a deep resonance with hospice's philosophy of care and vision of itself, Brenner says.

"I have heard some senior hospice executives say that there isn't a place for these patients in hospice because they can't be counseled or say whether they are in pain," Labyak says. "I'd say we need to do a self-check: Are we responding from our own fears?"

Hospice professionals are perfectly capable of doing Alzheimer's care, Stuart adds. And for those who find the work unfulfilling or feel frustrated in trying to provide quality of life for non-responsive patients, Stuart says the answer lies in soul-searching — literally. "When I used to make nursing home rounds every month, I would frequently see patients that I couldn't speak with. I needed to search for their souls," he relates. "Put your hands on their shoulders, stand behind them and feel how they're doing." Or put one hand on top of their head and one on their heart and try to find their souls, he says. "Who knows what you're actually feeling? What you're really doing is connecting with another person the best way you can," Stuart explains.

"I have no patience for people in hospice who have no willingness to do that. If you can't get fulfillment from the patient responding in your language of choice, then use the patient's language,"

he says. "It's no different than holding a crying baby or a sick pet. It boils down to love, and it's about healing — for them and for us. It heals the feeling of separation that might lead some hospice professionals to say: 'I don't get fulfillment from patients I can't communicate with.'" ■

How to determine eligibility in Alzheimer's

Guidelines offer some help

Defining a terminal prognosis of six months or less to live, as required for a hospice admission, is one of the biggest barriers to enlarging the role of hospice in Alzheimer's care. These patients have been gradually declining for many years, and there may not be an obvious transition point or dramatic changes in their condition that would signal the need to consider hospice care. **(For further discussion of the role of hospice in Alzheimer's care, see cover story.)**

However, *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases, Second Edition*, developed by the National Hospice Organization (NHO) in Arlington, VA, provides a good starting point in qualifying Alzheimer's patients for the Medicare hospice benefit. Meanwhile, research is under way that should bring additional clarity in this area — at least until legislative changes are made in hospice's six-months-or-less requirement.

David Lindeman, PhD, of the Rush Institute for Healthy Aging at Rush-Presbyterian-St. Luke's Medical Center in Chicago is coprincipal investigator of a new project that will study 1,500 Alzheimer's patients residing at 60 nursing homes nationwide. The goal is to develop a more refined model for estimating six-month survival rates. He hopes the research will "capture all clinical as well as policy-related data to not only identify if it's possible to create a model for estimating six-month survival rates, but also to make recommendations for providers and for family members on how to make informed decisions."

Ladislav Volicer, MD, PhD, and colleagues at the E.N. Rogers Memorial Veterans Hospital in Bedford, MA, also are studying the issue with funding from the Alzheimer's Association, with the goal of developing recommendations for policy changes in this area. But he urges hospices

not to shy away from Alzheimer's because "they can provide a lot of useful services within the current benefit."

NHO's medical guidelines for determining a terminal prognosis in chronic Alzheimer's or multi-infarct (stroke) dementias — as opposed to acute, potentially reversible dementias — start with functional status and the use of tools such as the Reisberg Functional Assessment Staging (FAST). Other such scales include the Karnofsky Performance Status Scale and the Global Deterioration Scale. According to NHO guidelines, an appropriate Alzheimer's patient for hospice would show all of the following characteristics:

- inability to ambulate without assistance;
- inability to dress without assistance;
- inability to bathe properly;
- urinary and fecal incontinence;
- inability to speak or communicate meaningfully, using more than six different intelligible words.

The first of these factors is the most critical one, according to the research, although a recent study suggests that the fifth trait, loss of meaningful communication, also is a key indicator of end-stage status. Other critical factors include difficulty in swallowing food or refusal to eat, and the presence of comorbid medical complications such as aspiration pneumonia, upper urinary tract infection, septicemia, or decubitus ulcers.

Can patient walk and talk?

Taken as a whole, the criteria suggest that appropriate hospice candidates with Alzheimer's disease will have lost the ability to walk and talk while comorbid conditions are starting to appear, says **Brad Stuart**, MD, hospice medical director for Home Hospice, a program of VNA and Hospice of Northern California in Emeryville and a primary author of the NHO guidelines. If more evidence is needed, Stuart suggests looking to elements of rapid decline in functional status. **(For further discussion of six-month determination, see *Hospice Management Advisor*, October 1998, p. 119.)**

The NHO guidelines and the Medicare local medical review policies based on them "have been criticized for being insensitive, and that criticism is valid," Stuart says. "If you use the standard of not walking and talking and the presence of medical complications, few patients will survive six months. But that standard leaves out many Alzheimer's patients" who will

Alzheimer's resources

Local Alzheimer's Association chapters or the national office in Chicago are among the best informational resources on the disease, both for family caregivers and health care professionals. Contact the association at 919 N. Michigan Av., Suite 1000, Chicago, IL 60611. Telephone: (800) 272-3900. Web: www.alz.org. The association also has published a guide for developing dementia programs, called *The Key Elements of Dementia Care*. Call (312) 335-5796 for ordering information.

Another source of information is the Alzheimer's Disease Education and Referral Center of the National Institute on Aging, P.O. Box 8250, Silver Spring, MD 20907. Telephone: (800) 438-4380.

Earlier this year Springer Publishing issued *Hospice Care for Patients with Advanced Progressive Dementia*, edited by Ladislav Volicer and Ann Hurley (320 pages; \$48.95 hardcover). The book addresses program implementation as well as clinical and ethical issues. Contact Springer at 536 Broadway, New York, NY 10012. Telephone: (212) 431-4370. Fax (212) 941-7842. ■

die within six months. The more experience hospices have using the criteria on these patients, the better they well get at applying them, he adds.

"Hospices are reluctant to admit these patients if they think they might have to discharge them in the future" when they no longer appear to fit the criteria, observes **Paul Brenner**, MDiv, coordinator of Jacob Perlow Hospice in New York City. "For most hospices, that's not OK. This is also not a time when they want to be taking risks, but in today's regulatory environment, it has to be OK."

Use of the NHO criteria need not be terribly difficult, says **Pat Whitney**, RN, MBA, director of St. Margaret's Hospice in Spring Valley, IL. "But if these criteria are in place, why aren't people putting their loved one into hospice? They've been taking care of their loved one for years, struggling on their own. By the time they get to the end, unless someone comes in and says, 'Hey, here's something that could really help,' they don't know." ■

Percent of Hospice Admissions with Cancer or Non-cancer Diagnoses

	<u>1992</u>	<u>1993</u>	<u>1994</u>	<u>1996</u>
Total current patients	52,100	50,100	61,000	59,400
Percentage with malignant neoplasms	65.7%	70.1%	56.9%	58.3%
Percentage of other (i.e., non-cancer)	34.3%	29.9%	43.1%	41.7%
Total discharges in 12-month period	219,300	257,200¹	328,000¹	393,200¹
Percentage with malignant neoplasms	74.7%	78.1%	69.0%	69.7%
Percentage of other (i.e., non-cancer)	25.3%	21.9%	31.0%	30.3%

1. Covers the fiscal year Oct. 1 to Sept. 30.

Source: National Home and Hospice Care Surveys, National Center for Health Statistics, Baltimore.

Declining non-cancer admissions

Last month's *Hospice Management Advisor* featured a cover story exploring questions about non-cancer admissions to hospice raised by former Washington, DC-based Hospice Association of America executive director **Diane H. Jones**, MSW, ACSW. Jones asked whether increased regulatory scrutiny in recent years has caused hospices to retreat from enrolling patients with diagnoses other than cancer. Although the issue remains vitally important to the hospice industry, subsequent information from the National Center for Health Statistics (NCHS) in Baltimore suggests that the statistical picture may be more complicated than *HMA* had portrayed.

NCHS tracks annual Medicare hospice admissions in two broad categories: based on current patients (i.e., on the rolls of the agency at midnight the day before the survey), and based on total discharges in a 12-month period. The two categories produce different results when it

comes to non-cancer admissions, but the gap between the two has remained relatively stable from year to year. The data from NCHS show a big jump in non-cancer admissions from 1993 to 1994, and a slight drop-off from 1994 to 1996 for both statistical categories. (See chart, above.)

Other evidence comes from **Stephen Connor**, PhD, vice president for research and professional development at the National Hospice Organization (NHO) in Arlington, VA. In NHO's 1995 Hospice Census, 40% of U.S. hospice admissions were non-cancer. In a 1996 "PDQ Survey" by NHO, with a much smaller number of responding programs (169 vs. 1,000), the non-cancer share of patients had shrunk to 32%.

"This is precisely the time period when Operation Restore Trust was going on, and scrutiny on non-cancer patients was increasing," Connor observes. "We've heard a lot of mixed reports, but the general feeling is that local medical review policies are now having a chilling effect" on non-cancer admissions. However, only time and subsequent surveys will tell whether non-cancer enrollments will continue to go down, he says. ■

Hospices offer power of touch

Massage therapy provided in varied ways

Interest in complementary or alternative therapies is booming throughout the U.S. health care system, and massage or touch therapy seems to offer the most common avenue for many hospices to start exploring their role in this area. In a survey of *Hospice Management Advisor* readers earlier

this year, they were asked to indicate whether they offered or planned to offer a number of complementary therapies; 44% said yes to massage/touch therapy. Massage programming is turning up more and more on the schedules of state and national hospice conferences, as well.

Hospices use massage therapy and other forms of therapeutic touch in a variety of ways. But they all face a number of basic questions, such as whether it is a covered service, whether it is written into the patient's plan of care, and when it is indicated as an appropriate therapeutic modality

for symptom management. Hospices also need to validate the credentials of massage professionals, train them in the hospice philosophy, and integrate them into the overall functioning of the hospice team.

The American Massage Therapy Association (AMTA) of Evanston, IL, defines massage as “manual soft tissue manipulation; includes causing movement and/or applying pressure to the body,” with the aim of increasing health and wellness. Different types of massage include Swedish and deep tissue massage, Shiatsu and acupressure, and reflexology or massage of certain points on the hands or feet thought to correspond with other areas of the body. Other types of touch therapy include therapeutic or healing touch and Reiki — a form of hands-on healing involving energy channeling.

Massage as a complementary health therapy does more than just make people feel good; increasingly, it is being integrated into medical practices and covered by insurance plans. Hospices are using massage therapy as an adjunct to pain management, to help prevent decubitus ulcers, and to treat patients’ anxiety, agitation, insomnia, or isolation. Family caregivers also may be targeted for massage if their stress level is high.

How do hospices utilize massage?

At Boulder County Hospice in Boulder, CO, massage therapy volunteers have been employed since the late 1970s. Credentialed massage therapists go through a hospice volunteer training course to orient them to the hospice philosophy and are required to take a course titled “Comfort Touch for the Elderly and Ill,” taught by **Mary Kathleen Rose**, CMT, a volunteer with the hospice since 1989 and currently its supervisor of massage therapy.

Comfort touch is a term Rose coined to describe her approach to touch therapy for the ill or elderly, which focuses on comfort, safety, and the use of slow, broad, gentle strokes — since the deep tissue work practiced in sports massage, for example, would be too painful for hospice patients. Massage therapists also must work on patients where they find them, without the benefit of a massage table.

“We view it as one more thing to add to hospice’s comfort package,” explains **Jackie Stipe**, the Boulder hospice’s human resources coordinator. “We address it like any other volunteer going into the home to provide companionship

or support, under the supervision of the nurse case manager. It complements what we already offer as far as palliative, comfort care and relaxation, and it’s immensely popular,” Stipe says. The hospice also utilizes student interns nearing the end of their classroom training, and refers bereaved survivors to a list of local massage therapists. Currently it has 18 massage therapy volunteers or interns under Rose’s supervision, and about a third of its caseload receives the service.

“I hear patients say this is the brightest spot in their week — just knowing someone cares enough to touch them. They sometimes say, ‘Nobody has ever touched me this way before,’” she adds. “The therapists tell us it feels so good to make such a difference in their patients’ lives.”

FirstHealth of the Carolinas Hospice in Pinehurst, NC, also offers massage services to its patients. But if the therapy is considered an appropriate part of the interdisciplinary team’s plan of care and approved by the attending physician, the hospice will pay for it, under contract with a nearby fitness center run by its parent health system. “We let patients know we have complementary therapies. They may have an interest and ask us about the option, or we may feel they need it” and recommend it to them, explains hospice social worker **Tina Markoff**, CCSW. “We discuss it as a team, then we definitely put it in the treatment plan.”

The North Carolina hospice also is developing a new pre-hospice program, emphasizing complementary therapies such as massage, yoga, Tai Chi, group therapy, and individual counseling, explains Options program coordinator **Judy Fore**. The program targets the problem of short length of stay in hospice by connecting with patients who have life-limiting illnesses before they are appropriate or ready for hospice care. “I think people need to start dealing with death and dying, grief, loss, and spirituality much sooner in the course of their illness,” Fore says. “We hope to pull together a community of people sharing these common concerns.”

The hospice at Kaiser Permanente HMO’s Walnut Creek, CA, medical center currently has three part-time massage therapists on staff, says hospice director **Valerie Ghirardo**, RN, MPA. They are part of its menu of ancillary services, including art and music therapy, which are offered to all hospice patients and paid with donated funds. “Most of our patients accept at least one ancillary therapy, and massage is very

popular,” Ghirardo says. “It’s just nice to have that touch. It means someone’s there to care for them, that they’re special.”

The hospice also uses massage for pain control, for emotional isolation, and just to help patients relax. “When we get a physician order, we look at the frequency of massage visits and use a problem, intervention, goal, assessment approach on the plan of care. The massage therapist also does progress notes,” she explains. “Massage therapists will tell you that they also do a fair amount of listening and counseling. When people are more relaxed, they tend to talk more. The therapists are very much part of the team — they come to team meetings and teach other staff about the benefits of massage.”

Massage also is appropriate for family caregivers, who sometimes experience such great stress, anxiety, or exhaustion that it physically tightens them up, says **Jan Sinn**, LCSW, social worker at Hospice of Bloomington, IN. “What’s important about massage is it can often be provided when there’s little communication going on between the patient and caregiver. Teaching simple hand or foot massage can help such caregivers interact with their dying loved ones,” Sinn observes. “It’s also an important provision of care when the patient is comatose or semi-comatose. The family finds it very rewarding to continue massaging the patient.”

Other issues for massage programs

Although hospice directors with massage programs report that they are popular with patients and well accepted by physicians, there are potential problem areas. One of these, Markoff says, concerns the number of visits made by the massage therapist. “It’s important to make it clear to the family up front that massage is an not unlimited benefit,” she says.

Another key question is how to pay for it, says **Emil Zuberbueler**, a registered massage therapist, administrative specialist with Family Hospice in Dallas, and allied therapies representative on the Arlington, VA-based National Hospice Organization’s Council of Hospice Professionals. “If you just use volunteers as massage therapists, they should go through the hospice volunteer training,” he says. “It is also important that they be appropriately credentialed in their state.”

Pikes Peak Hospice in Colorado Springs, CO, offers a full complement of massage and touch therapies, says its CEO, **Martha Barton**, RN. “But

Resources for massage information

Credentialed is a crucial issue for hospices attempting to add massage therapy to their service mix. State massage practice laws are now on the books in 27 states, and the American Massage Therapy Association of Evanston, IL, also has developed certification programs for massage therapy.

For information on state laws and related issues, contact AMTA’s home page on the Web: www.amtamassage.org. Other Internet resources include American Massage Magazine: www.massagemag.com; the American Holistic Nurses Association in Flagstaff, AZ: www.ahna.org; and the National Institutes of Health’s Office of Alternative Medicine: www.nih.gov.

Mary Kathleen Rose, CMT, a volunteer with Boulder County Hospice in Boulder, CO, and currently its supervisor of massage therapy, has written a 60-page booklet called *The Gift of Touch*, about Boulder County Hospice’s comfort touch program. This guidebook includes administrative, communication, and documentation guidelines for a massage therapy program, as well as techniques of comfort touch. The booklet is for sale at a cost of \$10 plus shipping and handling. Contact the hospice at 2825 Marine St., Boulder, CO 80303. Telephone: (303) 449-7740. ■

when we embraced the process more than 4 years ago, we decided we would only do it if we saw it as an extension of symptom control” for patients with complex symptom management needs, not just because it feels good to the patient. “We take massage very seriously. We will pay for hours of direct services and management. We also use as many volunteers as we can,” she says, adding that half of the agency’s current caseload benefits from the service.

“We just think it broadens our opportunity to achieve successful outcomes,” Barton says. “As we’ve tightened up in so many areas, this is one of those programs I’m working very hard to hold onto. We really do see that it translates into patient comfort.”

Zuberbueler believes that resistance to the idea of massage therapy by hospice professionals has

largely evaporated in recent years. "Enough has been in the media about alternative therapies. The federal government has two different organizations set up to look at the issues. I don't think many people today would say this is too far out. Ten years ago, yes. Then I would say I do massage therapy and they'd just laugh. That doesn't happen anymore, even in Texas." ■

Hyde bill opponents make some headway

NHO leads in opposing assisted-suicide measure

Palliative care advocates were expressing guarded optimism that their determined lobbying efforts had succeeded in slowing the juggernaut propelling H.R. 4006, the Lethal Drug Abuse Prevention Act of 1998, as this issue of *Hospice Management Advisor* was going to press. A floor vote in the House of Representatives had been postponed several times but was rescheduled for late September, with simultaneous markup of a companion bill, SB 2151, planned in the Senate Judiciary Committee. (For further discussion of the Hyde bill, see *HMA*, October 1998, pp. 121-122.)

September editorials in the *New York Times*, *Washington Post*, and *Los Angeles Times* all weighed in against what they described as misguided and heavy-handed legislation, raising hopes by opponents that they might yet mobilize sufficient opposition to derail it.

H.R. 4006 was introduced by Rep. **Henry Hyde** (R-IL) in response to a ruling earlier this year by Attorney General Janet Reno that the government would not use federal Drug Enforcement Administration (DEA) authority to punish physicians who participated in physician-assisted suicide. Currently, assisted suicide is legal only in the state of Oregon. Oregon's Death with Dignity law was the primary target of the Hyde bill, which would prohibit the dispensing or distribution of controlled substances for the purpose of assisting in a suicide. The bill also creates a structure within the DEA for investigating reports of such behavior and revoking the DEA controlled substance registration and privileges of physicians or pharmacists found guilty of assisting in a suicide.

Pain management advocates, including all of the national groups representing hospice and

palliative care professionals, have strenuously opposed the bill on the grounds it would chill the prescribing of controlled substances for terminally ill patients' pain — especially given the well-documented fears already held by many physicians about regulatory second-guessing of opioid prescribing. Even groups like the Chicago-based American Medical Association, with longstanding opposition to legalizing physician-assisted suicide, have declared H.R. 4006 the wrong vehicle for enacting such opposition.

The Arlington, VA-based National Hospice Organization (NHO) has played the lead role in convening a coalition of some 50 health care organizations opposed to HR 4006, and has hosted two briefings for congressional staff, one of which was covered on the *C-Span 2* cable TV network. In fact, Hyde acknowledged its effectiveness by singling out the "National Hospice Association [sic]" in a Sept. 18 Dear Colleague letter for "scaring physicians and members of Congress in believing that H.R. 4006 will prevent physicians from practicing proper pain care Don't let the National Hospice Association spread the rumor that the DEA will be knocking on every physician's door." Hospices should stick to making the end of life more comfortable for dying patients, Hyde stated, and stop trying to scare doctors.

Bill functions as conservative litmus test

This summer the Hyde bill was said to be on an almost unstoppable fast track through Congress. Right-to-life groups such as the Washington-based National Right-to-Life Committee had made it a litmus test for congressional social conservatives. **Joanne Lynn**, MD, director of the Washington-based Center to Improve Care of the Dying and another high-profile opponent of Hyde's bill, told the Portland *Oregonian* newspaper in September that Hyde and others are pushing the bill for political reasons, not because it is the best way to stop assisted suicide. "From their perspective, they're looking to deliver on some religious right agenda. And all their other bills have been bottled up."

At press time, pain advocates were saying that each day action on the bill was postponed increased their chances of mobilizing the opposition. However, **John Giglio**, NHO's director of public policy and general counsel, suggested that the best chance of stopping the bill was in the Senate, not the House. "I can say that the hospice community has answered the call, and Congress is starting to get the message," he told *HMA*. Oregon

Senator Ron Wyden was said to be threatening a filibuster against the bill, if that became necessary. The Clinton administration, which also opposes legalized physician-assisted suicide, weighed in with its opposition to the bill, in a letter from Acting Assistant Attorney General L. Anthony Sufin to the chairman of the Senate Judiciary Committee, Orrin Hatch (R-UT). Congress was expected to adjourn in early October for election year campaigning. ■

HCFA cost report draft perplexes hospice leaders

Another draft may be needed to fix discrepancies

Hospice leaders have expressed consternation over a draft hospice cost report released for comment in August by the Health Care Financing Administration (HCFA) in Baltimore — especially since hospice representatives had met with HCFA prior to its development to offer input and recommendations.

They say the draft report contains numerous line errors and misstatements, as well as leaving out some of the key recommendations they had discussed with HCFA staff. However, they express hope that the errors are inadvertent, not a reflection of some hidden agenda by the government. It seems probable, based on these concerns, that HCFA will need to issue a second draft of the cost report for additional comment, before finalizing it.

Members of the task force that worked with HCFA on developing the hospice cost report, including representatives from the Arlington, VA-based National Hospice Organization and the Washington, DC-based Hospice Association of America, reconvened in Washington in late September to go through the draft line by line to compile a detailed critique in time for the Sept. 30 deadline for comments. They also hope to meet in

person with Tom Hoyer, HCFA's director of the Office of Chronic Care and Insurance Policy, to amplify their concerns.

"There are multiple errors in the cost report draft, such as references to lines that don't exist," says **Teresa Craig**, CPA, vice president for finance and MIS at Hospice Inc. in Wichita, KS, and a member of the cost report task force. A number of pages seem to have been copied straight from skilled nursing facility or home health agency cost reports, with only partial adaptation to hospice regulations, she says. "It's kind of a mess, and frankly, I'm disappointed. Maybe all of the other things going on in HCFA resulted in the creation of a document that is less than satisfactory," Craig speculates, adding that she hopes the final product will turn out to be easier for hospices to understand and complete.

A new cost report for Medicare-certified hospices was mandated by Congress in last year's Balanced Budget Act, and was due to go into effect starting with providers whose fiscal years began Oct. 1, 1998, with their first cost reports due 17 months after that date. However, implementation already has been set back six months by HCFA, and likely will need to be delayed even further. There was not enough time to develop electronic standards for submitting the hospice cost report, so the reports will have to be submitted manually.

Do Medicare rates reflect costs?

A primary aim for the new hospice cost report is to determine whether current Medicare reimbursement rates reflect the actual costs of providing hospice care. That is why hospices are vexed over statements in the published draft that bereavement and volunteer services are "required hospice services" but are not reimbursable. The task force hopes to clarify what this really means, given hospice's all-inclusive per-diem reimbursement structure, Craig says.

Regardless of how the controversies are

(Continued on page 140)

COMING IN FUTURE MONTHS

■ Update on HIV disease and hospice

■ Integration/disintegration

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■ The family caregivers perspective

resolved, she says, time sheets to allocate hospice staff time and costs of providing different levels of care and administrative overhead still will be important. HCFA's draft cost report does not break down costs between patients residing in nursing homes or their own homes, but she recommends that hospices start tracking such data. Craig urges hospices not currently tracking their professional staff's time and costs to start doing so because these data eventually will be necessary for completing the mandated cost report. **(A sample time sheet for field staff is presented on p. 138.) ■**

NEWS BRIEF

Hospice answers Hemlock accusation

Winthrop Thies, founder and president of the Hemlock Society of New Jersey in Maplewood, was detained by Union County authorities in September at the Westfield, NJ, home of a terminally ill cancer patient who, Thies said, was planning "self-deliverance." Thies apparently intended to test the constitutionality of a 30-year-old state law against aiding in suicide.

Officers later confiscated the woman's drugs before suicide could be attempted. A Hemlock press release claims that the officers then "forced her" to go into Father Hudson's House, a residential hospice facility operated by Center for Hope Hospice in Linden, NJ. The hospice's director, **Peggy Coloney**, in a Labor Day interview with **Don Pendley**, president of the New Jersey Hospice and Palliative Care Association, hotly disputed that any patient had ever been forced into the facility. A spokesperson for the Union County Prosecutor's office confirmed that the terminally ill woman "chose hospice of her own volition."

"The largest problem here is the apparent misrepresentation of how the woman entered hospice," Pendley tells *Hospice Management Advisor*. "Clearly, Hemlock wanted to create a test case. The woman had requested confidentiality, and Hemlock violated that request," he asserts. ■

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