

HOSPICE Management ADVISOR

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HHS is spreading the word to bolster the use of hospice

Agency clarifies Medicare hospice benefit for reluctant physicians

One of the roadblocks to appropriate hospice admission has always been the six-month terminal illness diagnosis. Physicians complain that making such a prognostication amounts to fortune-telling and that patients can often live longer than six months, even with a certification of terminal illness.

Hospices have responded to reluctant physicians by attempting to explain that certifying someone as terminally ill doesn't mean they have to die within six months. Rather, it means there is a strong likelihood that the disease will claim a patient's life but that it's acceptable for a patient to live more than six months after certification of terminal illness.

With average lengths of service remaining static for the past few years, it is obvious that hospice efforts have fallen on deaf ears. There is renewed hope, however, that the message will finally take root and spread among physicians so that terminally ill patients will be referred to hospice sooner. The reason for that hope is a message that the U.S. Department of Health and Human Services (HHS) is delivering directly to physicians and consumers.

In a letter sent to a variety of physician trade associations, HHS Secretary **Thomas A. Scully** advised physicians to consider hospice care for their patients sooner and not to misinterpret the terminal illness requirement.

"We are concerned that some individuals who may want hospice care, and could benefit from it, may not be learning about it or may be learning about it too late in the course of their illness," Scully wrote. "Therefore, we are requesting that members of the physician community, as well as other health care professionals, think more about hospice as they care for terminally ill patients."

Scully attempted to assuage physician concerns about making inappropriate hospice referrals. "We recognize that making these determinations is

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not an exact science and that the impact of hospice services may, initially, improve the patient's condition," Scully wrote. "Thus, Medicare regulations use the terms 'expectancy' and 'if the terminal illness runs its normal course' in its definition to indicate that it is entirely possible for hospice services to be needed for more than a six-month period. The Medicare program recognizes that terminal illnesses do not have entirely predictable courses."

To further emphasize its point, the Centers for Medicare and Medicaid Services (CMS) published articles in the *Physicians Executive Journal*, *McKnight's Long Term Care News*, and *Caring Magazine*. The articles provide information about the benefits of hospice care and reinforce CMS' message that appropriate end-of-life care must be provided to terminally ill patients.

"This is important, because the regulator of the industry is saying the benefit is unlimited and should be considered for patients," says **Jonathan Keyserling**, vice president of public policy and communications for the National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA. "[HHS] could have simply issued a dry program memo, but they really stepped up to ensure the message reached those who needed it the most."

A memo extolling the virtues of hospice is nothing new, though. **Nancy-Ann Min DeParle**, the former administrator of the Health Care Financing Administration (now CMS), wrote a similar letter to the NHPCO in September 2000. In that letter, she said the hospice Medicare benefit was not restricted to six months of coverage; there was no limit for a beneficiary to receive coverage so long as he or she met the eligibility criteria; and a beneficiary could receive hospice care for longer than six months as long as the physician properly recertifies the six-month terminal illness prognosis.

In fact, some of the wording in Scully's letter seems to have been pulled directly from Min DeParle's letter. While Keyserling praises Min DeParle's support of hospice and her effort to clear up misconceptions about the hospice Medicare benefit, the message didn't reach those who needed it most — physicians. The letter served to reaffirm truths that, while known among hospices, were contested at the time. Federal investigators had looked at a few hospice programs and applied a narrow interpretation of the Medicare Hospice Benefit, which led to the conclusion that hospices were admitting patients who were ineligible for the benefit.

"Min DeParle made it clear that prognosis is not an exact science and that the benefit is unlimited," says Keyserling. "Unfortunately, the letter was directed to hospices."

Keyserling credits the current administrator's open-door policy for expanding the message beyond hospice and says there is an ongoing dialogue between the HHS administration and hospice leaders regarding the Medicare hospice benefit.

Spreading the word

Keyserling and other industry experts say hospices should use Scully's letter and the newly published articles to reinforce the message they have been giving physicians for years. In fact, the NHPCO has also notified more than 200 health care organizations of the CMS administrator's recent clarification via a "Dear Colleague" letter.

"It was a wonderful endorsement of hospice," says **Lisa Spoden**, PhD, MBA, executive director of the Kentucky Association of Hospices and Palliative Care in Lexington, and vice president of Strategic Health Care in Columbus, OH.

Hospices should give referring physicians copies of the articles and Scully's letter to ensure the message reaches them. At Hospice of Central Iowa in West Des Moines, administrator William Havekost is using the Scully letter to educate the hospice's fiscal intermediary, which has disagreed with the eligibility of some of its patients. But Spoden says sharing letters and articles will only go so far and that hospices need to nurture their relationships with physicians to change their referral habits for the better. Hospices can do this by going to greater lengths to identify and meet physician needs and fulfill them.

These needs include:

- basic hospice information;
- an easy referral process;
- frequent updates about patient condition;
- pain management information;
- timely responses to orders and requests.

"Most physicians are unsure of how hospice is financed. We hope that by informing physicians how this works that we will help to decrease late referrals," says **Sally Aldrich**, RN, MSN, director of Methodist Alliance Hospice in Memphis, TN. "What we are trying to do is promote more communication."

Spoden agrees that communication is important. She advises hospices to designate a single

person to be responsible for communicating with physicians. The physician liaison should have a health care background and be a member of the hospice's administration, she says. This is important to encourage physicians to be confident in the information being provided to them, Spoden says.

"It takes a special kind of nurse to do this job," Spoden says. "You need someone who is open to opportunity, a problem-solver."

Methodist Alliance Hospice assigns a marketing person to the task of physician communication. But the position goes far beyond traditional notions of communicating the hospice philosophy. Aldrich says the physician liaison at Methodist Alliance Hospice is responsible for communicating admissions guidelines to physicians and explaining the Medicare hospice benefit.

By educating physicians on proper hospice admission, Methodist Alliance Hospice has been able to add days to its median length of service. Two years ago, the hospice had an LOS of 25 days. Last year its LOS rose to 29 days, says Aldrich. Since then, the median length of service has dropped to 20 days. ■

Liaisons can smooth out communication with docs

Follow-up surveys also can improve performance

The need to pass on advice from the Department of Health and Human Services about interpretation of the six-month rule accentuates a basic challenge that hospices face constantly: communication with physicians.

At Methodist Alliance Hospice in Memphis, TN, a physician liaison is responsible for communicating basic hospice information such as the role of the treating physician in hospice care. The marketer also gives physician information demonstrating the cost-effectiveness of hospice care.

Understanding that continued improvement will help bring more referrals, the hospice also tracks physician satisfaction. Following a patient's death, the liaison surveys the treating physician to track ease of referral, responsiveness to physician needs, and level of communication.

Since the hospice has begun tracking physician satisfaction, physician response has prompted improvements in the hospice's referral and intake

process. "We've streamlined our process," says **Sally Aldrich**, RN, MSN, hospice director.

The most notable change has been the elimination of several phone numbers. Now, physicians and hospital discharge planners have only one number to call and are directly connected to personnel who can help. Another change has been to add night-time admission in an effort to accommodate physicians and hospitals seeking hospice care outside normal business hours.

Acknowledging physicians for their referral is important, as well. Following a patient's death, a list of hospice services rendered to the patient and family during their stay can be sent to the physician, says **Lisa Spoden**, PhD, MBA, executive director of the Kentucky Association of Hospices and Palliative Care in Lexington. The correspondence should give information on the number of visits made by nursing staff, social workers, chaplains, and other volunteers; bereavement follow-up; who was present at death; and a personal, handwritten note by a coordinator or administrator thanking the physician and staff.

Experts offer a similar system to nurture physician referrals:

- Members of the administrative team are assigned key doctors.
- The team member is responsible for establishing a working relationship with doctors or key members of the doctor's staff.
- The means and frequency of communication should be determined between the hospice staff member and the doctor/doctor's staff member.
- The team member communicates patient care issues, assesses physician/patient needs, and relates new program ideas within these established guidelines.
- The team member reports findings to hospice leaders.

It is important to give clinical and administrative staff feedback from all referral sources, such as changes in managed care policies, physician feedback, and updates on changes in the marketplace, says Spoden.

"The purpose is to help staff realize that your referral resources are important to your program," Spoden says.

Another approach to effective physician relations is to think of the referring physician as a customer on the same plane as patients and families.

Like patients and families, physicians have a set of priorities for dealing with hospice and hospice staff. These include:

- keeping physician paperwork to a minimum;
- hospice staff making sound, independent decisions regarding the care of their patients without having to consult the physician for minor questions;
- when physician consultation is needed, staff providing detailed information and proposing specific solutions for physician approval;
- good communication, including regular updates from hospice staff regarding patients' condition.

Most hospices may think they are doing the things that compel physicians to refer patients to their hospice regularly. Yet, the only way to find out whether or not those needs are being met is to actually ask physicians if they are satisfied with the care provided to their patients and with the support given to them.

Start by tracking referrals of all referring physicians, and look for physicians whose referrals have dropped off from month to month or over the course of a year. If they aren't referring patients with the same frequency, the hospice must find out why. If the hospice's tracking system identifies a physician whose referrals have declined over several months or after an annual review of referrals, a hospice representative should be dispatched to the physician's office to find out why referrals have diminished. ■

MedPAC: Payment evaluation needed

Report paints a 'rosy' picture of patient access

MedPAC, the congressional advisory panel on health care delivery and financing, has called on the U.S. Department of Health and Human Services (HHS) to evaluate the adequacy of Medicare's payments to hospices for providing end-of-life care to patients and families.

While the agency's recommendation has been welcomed by hospice industry leaders, its largest trade association criticized MedPAC for potentially downplaying the access problems hospice currently face.

"The report inadequately addresses the complex factors that often prevent patient access to end-of-life care," the National Hospice and Palliative Care Organization (NHPCO) said in

a press release. The statement came days following the June 17 release of MedPAC's report to Congress, "Medicare Beneficiaries' Access to Hospice."

No word yet from HHS or the Center for Medicare and Medicaid Services on what steps, if any, will be taken as a result of MedPAC's recommendations.

MedPAC is an independent federal body that advises Congress on issues affecting the Medicare program. The 17-member commission meets publicly to discuss policy issues and formulate recommendations to Congress on improving Medicare policies. The report is the result of the Benefits Improvement and Protection Act adopted by Congress in 2000. In that act, Congress charged MedPAC with examining the factors affecting the use of hospice benefits under the Medicare program. These include delays in the time (relative to death) of entry into a hospice program, differences in use between urban and rural hospice programs, and the presenting condition of the patient.

In its hospice report, MedPAC made two specific recommendations to HHS, which administers the Medicare program:

- **Evaluate hospice payment rates to ensure they are consistent with the costs of providing appropriate care.**
- **Research differences in the care and resource needs of hospice patients and determine whether a case-mix adjusted payment system for hospice is feasible, and study ways to establish a high-cost outlier policy.**

Hospice providers are concerned with the report because Medicare beneficiaries' access to hospice care was not comprehensively assessed, says **Jonathan Keyserling**, vice president of public policy and communications for the NHPCO, in Alexandria, VA. Specifically, the NHPCO takes issue with the way MedPAC depicted growth in the industry. The report illustrated growth in terms of the numbers of hospice providers and patients served, which have increased over the years.

"It does not actually determine the number of patients who never accessed or never learned of hospice care," NHPCO said.

As a whole, access has increased, according to the MedPAC report. The agency cites the tripling of hospice services in 2000 compared to 1992 and an increase in Medicare beneficiaries using hospices from 9% in 1992 to 23% in 2000, including 60% of beneficiaries who died from cancer in 2000.

But the NHPCO argues that the numbers may mislead Congress. While MedPAC statistics point to increased access, the numbers may simply be a reflection of the growing number of Medicare beneficiaries as a result of the graying of the American population.

It would be more accurate, NHPCO says, to look at the number of patients who do not receive hospice care or who don't receive information about hospice services until too late in the disease process, says Keyserling.

"They didn't take the additional step of looking at those who didn't use hospice," Keyserling says. "By ignoring the substantial number of people who don't have access to hospice care, it may paint too rosy a picture about the path to hospice."

Looking beyond supply and demand

The problem seems to lie in the two indicators of hospice access used in MedPAC's report: use of services and supply of providers. Essentially, MedPAC graded access on whether supply met demand. While the supply of hospice services has kept pace with the growing number of Medicare beneficiaries, there still are too many patients who are denied access simply because they aren't given proper information or information is not given in a timely manner, Keyserling maintains.

This seems to be borne out in a separate survey of health care consumers who wanted hospice information sooner than they got it. The survey, conducted by NHPCO, showed that nearly nine out of 10 Americans favor a consultation with end-of-life experts to inform patients with life-limiting illness of their care options.

The results of the survey, which was done in conjunction with the Harris Interactive polling company, were released in February 2000. It was conducted to look at the Medicare Hospice Benefit 20 years after the federal government began reimbursing hospices for the care they provide to terminally ill patients. The results corroborate an earlier study done by the National Hospice Foundation, the charitable arm of the NHPCO.

Of the 88% of respondents who support end-of-life consultations, most cited a belief that the information provided during the consultation would result in increased control over decision-making, improved quality of life, and alleviation of financial concerns.

Despite the criticism, the hospice industry is applauding the recommendations made by MedPAC. "NHPCO welcomes MedPAC's recommendations to review and evaluate alternative Medicare reimbursement mechanisms for hospice services," said Keyserling.

The MedPAC report addressed the issue of short length of service and how it negatively impacts hospice because hospices are unable to recoup their costs when the admission and the days surrounding a patient's death — the two most expensive periods of patient care — are too close to each other.

It also suggested in its recommendation for reimbursement evaluation that payment for services furnished to a patient living in a nursing home be reviewed.

One concern of hospice experts, however, is the use of cost reports to review costs. The NHPCO is concerned that the relatively new hospice cost reports will not paint an accurate picture of hospice costs, which could lead to unfair reimbursement.

Hospice reimbursement doesn't cover costs

One of the pieces of evidence MedPAC considered was the 2000 Milliman & Robertson report on how hospice costs have changed since the inception of the Medicare Benefit rule.

According to a study of 10,000 patients cared for in large hospice settings, the current reimbursement rate for routine home care, which accounts for 95% of hospice days used by Medicare patients, does not cover the costs incurred by hospices. It also found that the gap between what hospices are paid and how much it costs to deliver care poses a real threat to hospice programs nationwide.

M&R compared cost data from 1982, when the Medicare hospice benefit was first established, with cost figures from 1998-1999. The study pointed out a number of areas in which Medicare failed to keep up with hospice costs:

- **Patients are enrolling in hospices later.** With patients electing the hospice benefit closer to the time of death, there is less revenue opportunity for hospices. According to the study, the average length of service has dropped to 40 days, while the original Medicare hospice benefit set the original rate based on a 70-day length of service.

- **New technology.** Advances in technology, breakthrough therapies, and prescription drugs have increased the cost of hospice care far beyond

Medicare's annual market basket update, which is used to determine annual reimbursement increases. While the hospice per diem rate has doubled since the early 1980s, prescription drug costs, for example, have risen 1,500%.

- **An increase in outpatient hospital therapies.** The advent of palliative care chemotherapy and radiation treatment increased cost per day to more than \$17 per day. Medicare originally envisioned outpatient therapies to account for about \$3 of the per diem reimbursement.

Armed with the best evidence the industry has ever had to show that Medicare's per diem reimbursement is out of step with the scope of care hospices provide today, the NHPCO is now trying to persuade Congress to raise per diem rates to reflect today's needs.

Hospice drug costs rising 18.3% per year

The MedPAC report raises three points the hospice industry hopes lawmakers will consider:

- **Increasing cost of prescription drugs.** In 1982, when the hospice benefit was established, prescription drug costs amounted to about \$1 of the \$41.46 per diem payment. Today, prescription drug costs have soared to \$16 per day of a \$98.96 per diem payment.

"Drug costs have skyrocketed, making pain relief and symptom management — cornerstones of hospice care — much more expensive. Many of the most effective and widely used drugs for relief of cancer patients' discomfort are shockingly expensive," the NHPCO wrote in a press release that followed the unveiling of Milliman and Robertson's interim study results.

Many lawmakers want beneficiaries to get a break from rising drug costs. Depending on the source of information, drug costs are increasing 15% to 20% per year, experts say. Hospice drug costs are rising 18.3% per year, according to Hospice Pharmacia, a Philadelphia-based consulting firm. Because drug costs make up a significant portion of a hospice's direct costs, Hospice Pharmacia predicts those expenses will likely double in three to five years if left unattended.

Experts blame a combination of factors for the rising cost of drugs: higher drug utilization, inappropriate prescribing practices, and an increasing elderly population.

- **Declining length of service.** When Medicare set the rate for hospices in the early 1980s, it estimated a 70-day length of service, compared to the current average of 40 days. Hospices have suffered

from short lengths of stay and have struggled to come up with ways to bring patients into care sooner. Most hospice leaders blame current eligibility requirements that force physicians to make the uncertain prediction that a patient will die within six months as a result of their illness. In addition, reimbursement rules also mean physicians lose revenue as a result of a hospice referral.

Declining length of service exacerbates the already low reimbursement rate, widening the gap between cost and reimbursement. That's because hospices encounter higher costs in the first few days following admission and in a patient's final days. Per diem payments are often not enough to cover the cost of program introduction at admission and intensive care at the end of a patient's life.

- **Outpatient hospital therapies.** The advent of more innovative and expensive palliative care methods, such as palliative chemotherapy and radiation treatments, has contributed to the increase in hospice costs. With hospices filing cost reports this year, Medicare administrators will have their own hospice cost data to help them determine future reimbursement. While critics scoff at the reliability of cost report data, at least for the first few years, Keyserling welcomes more data.

"The more data that is collected, the better we will be able to show what hospices are going through," he said. "The [Milliman and Robertson] report is an attempt to show that current reimbursement does not reflect current practices." ■

Massage therapy can have emotional benefit

Power of touch is often understated

Most people know massage therapy for its relaxation benefits, but its application to hospice care goes well beyond the physical. The power of therapeutic bodywork can help dying patients release pent-up emotions, such as fear and anger.

"Massage therapy is very compatible with hospice care," says **Adela Basayne**, LMT, a private-practice massage therapist in Portland, OR. "Massage therapists aren't looking to change the health status of patients. Instead, their goal is to treat symptoms."

According to the National Hospice and Palliative Care Organization's Complementary Therapies in End-of-Life Care, hospice patients and caregivers exhibiting the following signs may benefit from massage therapy as a means of physical relief and psychosocial benefit:

- anger about the diagnosis;
- anxiety about pain, finances, or other matters;
- denial of diagnosis or progression of disease;
- fear of death;
- guilt;
- mood swings caused by pain drugs or disease-related dementia;
- depression;
- thoughts of suicide.

Massage therapy's applicability to pain management was supported in a 2000 study originally published in the *Hospice Journal*. Researchers studied 56 hospice patients whose average age was 64. Patients were randomly assigned to receive either massage therapy or usual care that did not include massage therapy. Those receiving massage therapy were given the therapy twice weekly for two weeks by a licensed massage therapist.

Pain decreased more in massage group

When the study began, about half of the patients had constant pain. Massage therapy and normal care both reduced patients' pain to episodic or intermittent pain in 14% of the patients in each group. Overall, patients suffered half as much pain at the end of the study as they did at the beginning.

But pain intensity decreased more in the massage group than in the usual care group — a 42% decrease in the massage group vs. a 25% decrease in the usual care group. Nearly three-quarters of the patients receiving massage reported pain levels of 0 or otherwise lower than at the beginning of the study, compared with only 57% of the usual-care patients.

About one-third of the massage patients received massages in between the sessions scheduled as part of this study. The effect of massage on pain intensity was immediate, according to researchers, decreasing the pain scores after each massage. Pulse rate and respiratory rate also fell, indicating a relaxation response.

The therapists followed a standardized protocol for the massage, specifying full-body massage, when possible, and the types and duration of the strokes to be used, such as effleurage strokes and others. The massages lasted 30 to

45 minutes. About half of the patients could not complete the study because death intervened or their condition deteriorated to an extent that precluded their completing the study questionnaire.

Hospice patients are not the only ones who can benefit from massage therapy. Caregivers, many of whom are under relentless stress, may enjoy physical and emotional improvement as a result of massage.

A 1998 study by The Oregon Hospice Association and East-West College of the Healing Arts, both in Portland, found that massage reduces physical stress, emotional stress, pain, and insomnia among primary caregivers for terminally ill family members.

Massage was offered to a group of 13 caregivers between the ages of 35 and 82 who had been referred by a volunteer coordinator or social worker. Most participants were women, mostly wives caring for husbands. They received 75-minute sessions of Swedish massage and other techniques, including shiatsu, Reiki, polarity, jostling, compression, myofascial release, trigger-point therapy, and gentle stretching, weekly or biweekly at a hospice or at their home. Half of the participants had never had massage before. On the intake form, caregivers primarily asked to have their necks, shoulders, or backs massaged. The average number of massages received was six (the caregivers were often too busy to take time for massage).

Assessments included a pre- and post-massage list of questions that rated emotional stress, physical stress, physical pain, and sleep difficulty on a 1-5 scale. Physical stress measurements included things such as stamina and energy level, while physical pain referred to specifics such as headaches, back pain, and knotted muscles.

Results showed that 85% of the caregivers reported a decrease in emotional and physical stress. Physical pain was relieved for 77% of the caregivers. Difficulty sleeping was eased for 54% of the study group. The few caregivers who reported contradictory results also commented on having so much stress from their daily duties or as a result of a recent death that they were unable to feel the benefits of massage beyond the immediate session.

The study concluded that participants experienced an overall decrease in stress and that by offering massage as a respite intervention, hospice agencies would benefit both caregivers and the patients under their care.

The reason for the positive results, says Basayne, is that both patients and caregivers are touch-deprived as a result of their disease and the demands of caring for a loved one. Friends and family members are less inclined to embrace, caress, or even hold hands out of irrational fear of contracting the same disease or some other personal reasons. Massage therapy brings back the human touch that patients are craving, says Basayne.

The reasons why massage therapy reduces pain are well-known, Basayne says. Experts have theorized that massage therapy's relaxation effect reduces anxiety, which in turn lowers pain intensity. ■

Patients kneading a massage? Here's a primer

Find therapists trained in 'informed touch'

Massage therapy is a broad term that describes a discipline encompassing a number of techniques, says **Adela Basayne**, LMT, a private practice massage therapist in Portland, OR.

The type of massage therapy most commonly used to treat anxiety and pain is traditional European massage, which includes methods based on conventional Western concepts of anatomy and physiology and soft tissue manipulation. There are five basic kinds of soft tissue manipulation techniques:

- effleurage (long flowing or gliding strokes, usually toward the heart, tracing the outer contours of the body);
- petrissage (strokes that lift, roll, or knead the tissue);
- friction (circular strokes);
- vibration;
- tapotement (percussion or tapping).

Swedish massage is the most predominant example of traditional European massage, and it is the most commonly used method in the United States. It was developed by Per Henrik Ling in Sweden in the 1830s and uses a system of long gliding strokes, kneading, and friction techniques on the more superficial layers of muscles. This massage usually goes in the direction of blood flow toward the heart, because there is an emphasis on

stimulating the circulation of the blood through the soft tissues of the body. Swedish massage can be relatively vigorous, sometimes with a great deal of joint movement included.

Oil is usually used to facilitate the stroking and kneading of the body, thereby stimulating metabolism and circulation. Swedish massage's active and passive movements of the joints promote general relaxation, improve circulation and range of motion, and relieve muscle tension. Swedish massage is often given as a complete, full-body technique, though sometimes only a part of the body is worked on.

Hospices, however, may encounter more recently developed disciplines. Among them is contemporary Western massage. This includes methods based primarily on modern Western concepts of human function, anatomy, and physiology, using a wide variety of manipulative techniques. These may include broad applications for personal growth, emotional release, and balance of mind, body, and spirit, in addition to traditional applications. These approaches go beyond the original framework or intention of Swedish massage. They include Esalen or Swedish/ Esalen, neuromuscular massage, deep tissue massage, sports massage, and manual lymph drainage. Most of these are American techniques developed from the late 1960s onward, though manual lymph drainage was developed in the 1920s.

Esalen and Swedish/Esalen massage are recent variations that focus not so much on relieving muscle tension or increasing circulation as on creating deeper states of relaxation, beneficial states of consciousness, and general well-being. Swedish is more brisk and focuses on the body; Esalen, on the other hand, is more slow, rhythmic, and hypnotic, and focuses on the mind/body as a whole. Esalen massage is not widely taught as a pure form. Rather, a marriage of sorts has been formed by the integration of Swedish and Esalen as a way of incorporating the strengths of each. Many massage therapists describe their method as Swedish/Esalen, and this hybrid is commonly taught in massage schools.

Neuromuscular massage is a form of deep massage that applies concentrated finger pressure specifically to individual muscles. This is a very detailed approach, used to increase blood flow and to release trigger points, which are intense knots of muscle tension that refer pain to other parts of the body (they become trigger

points when they seem to trigger a pain pattern). This form of massage helps to break the cycle of spasm and pain and is often used in pain control. Trigger point massage and myotherapy are varieties of neuromuscular massage.

Deep tissue massage is used to release chronic patterns of muscular tension using slow strokes, direct pressure, or friction. Often the movements are directed across the grain of the muscles (cross-fiber) using the fingers, thumbs, or elbows. This is applied with greater pressure and at deeper layers of the muscle than Swedish massage, which is why it is called deep tissue. This form of massage is also more specific. For example, in the case of someone with a sore shoulder, the practitioner may focus on the trapezius and the rhomboid underneath, trying to work in all the layers of muscle that might be involved. Deep tissue massage lends itself to being more focused on a problem area.

Basayne warns that uneducated amateurs may try to pass themselves off as trained massage therapists. Hospices should require national certification in massage therapy or proof of licensure in states that require massage therapists to be licensed.

"You want a massage therapist with training in pathology," Basayne says. "They need to understand the disease process and have an understanding of end-of-life care."

This is important, because a poorly trained massage therapist can add to a patient's pain rather than help relieve it. Basayne recalls an AIDS patient she treated a few years ago who benefited from massage in the early stages of therapy. But as the disease progressed, she was limited in the places she could manipulate.

"By the end, I was just caressing his head and neck," she says. "A therapist is trained in informed touch. A therapist has to determine tolerance to touch." ■



Consortium helps members provide grief support

Challenges of meeting grief needs

By **Robin McMahon**, LCSW, BCD
Senior Advisor for Grief and Loss Services
The Hospices of the National Capital Region
Fairfax, VA

One of the challenges faced by hospices is a community expectation of hospice as a resource to address grief issues related to life transitions. Individuals facing their own or a loved one's serious illness, death, and grief frequently contact their local hospice for information and referrals beyond the scope of hospice program services. When these queries arise, "Sorry, we don't do that" is not an acceptable answer within the culture of hospice caregivers.

We try mightily as clinicians and organizations to identify appropriate referrals. However, being responsive to community information calls can overburden the limited resources of most hospices. A hospice can balance its commitment to its patients and families while answering community calls by maintaining a list of area grief

and loss services and collaborating with other providers to establish programs where gaps exist between needs and resources.

Like other hospices, The Hospices of the National Capital Region, which serves Washington, DC, and its Maryland and Virginia suburbs, established a grief counseling center to try to address community needs related to life transitions. When we launched the center three years ago, one of our first actions was to invite all individual practitioners, institutions, and agencies offering grief support to join a consortium of providers.

Our hope was to stay current on available grief support services, to avoid duplicating existing effective services, and to identify unmet needs and collaborate on new services to fill in the gaps. Our partners include other grief counseling centers and government-funded grief programs, self-help organizations (such as Compassionate Friends) for parents whose child has died, faith community bereavement providers, private practitioners who specialize in grief issues, local hospitals that offer bereavement services, a transplant organization, a women's counseling center, and more.

Though we meet no more than three or four times a year, members of the group provide a valuable network of information and assistance to one another. This was evident on Sept. 11 as agencies responded to the community's bereavement needs. In addition, consortium members have supplied expertise to one another's programs as speakers, hotline volunteers, and even

as grief support facilitators following a significant death that occurs within one of the consortium agencies.

Based on requests for bereavement services in Spanish and groups for widows and widowers under 50, we initiated specialized groups to address these previously unmet needs.

In order to financially support the referral and counseling functions of the grief counseling center, The Hospices has sought grant funding, sliding scale fees for some of its services, donations from the community, and financial support from within the hospice itself. We rely heavily on volunteers to assist with our camps and workshops for children and teens. And in recent years we have found that student interns — that is masters' level students in social work, counseling, pastoral counseling, and gerontology — are excellent grief counselors and group facilitators when paired with a seasoned clinician.

Community resources

The majority of the inquiries our hospice program receives about grief support services fall under approximately seven general categories:

- loss issues of the newly diagnosed and family members, or individuals whose condition seems to be deteriorating;
- specialized losses (e.g., death of a child, miscarriage, violent death, suicide);
- elderly people who are experiencing other losses;
- children and teens and personnel in their schools;
- how to support someone who is grieving;
- bereaved people who have social, mental health, financial, housing, and legal needs;
- family members and friends who live out of state.

While resources vary from state to state and city to city, many of the referrals that are made in metropolitan Washington have counterparts in other areas of the country. Wherever possible in the list below, I have included toll-free numbers for national organizations that will specify the appropriate resources in your area.

Diagnosis of a life-threatening or chronic illness creates losses for the individual diagnosed and for loved ones. It is common for our hospice to receive calls from those affected who are seeking information and support. Contacting an organization formed to address a specific diagnosis, such as cancer, Lou Gehrig's disease, or Alzheimer's disease, generally yields a tremendous amount of information about the illness, a list of available support groups, and comfort that there are others who understand.

Here are a few of the toll-free numbers and web sites for the more prevalent diagnoses. Some organizations have on-line chat rooms that can be a great support, particularly for someone suffering from a rare disorder that may not have a local organization.

• **ALS Association:** (800) 782-4747, www.alsa.org

• **Alzheimer's Society** (information about the society): (800) 438-4380, www.alzheimers.org

• **Alzheimer's Association** (information about support groups): (800) 272-3900, www.alz.org

• **American Cancer Society:** (800) ACS-2345, www.cancer.org

• **American Diabetes Association:** (800) 342-2383, www.diabetes.org

• **American Heart Association:** (800) AHA-USA1, www.americanheart.org

• **American Stroke Association:** (888) 4 STROKE;

• **Arthritis Foundation:** (800) 283-7800, www.arthritis.org

• **National Parkinson Foundation:** (800) 327-4545, www.parkinson.org.

• **Specialized losses.** Most hospices and other grief counseling programs have drop-in bereavement groups, where anyone who has experienced a loss through death is welcome. However, the ideal in grief counseling and support is to participate in groups with other grieving persons whose loss or circumstances are similar to yours. This is particularly true for deaths that occur outside the expected normal life cycle.

For parents who have lost a child of any age, a group specific to grieving parents is important. In fact, many parents say there is a tremendous

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difference between the death of a young child and the death of an adult, and prefer to share with others experiencing a similar grief. Compassionate Friends is a national self-help organization for parents whose child has died. For stillbirth and miscarriage, the neonatal/perinatal department of your local hospital or your OB/GYN office should have information about local resources, including Compassionate Friends. The web site for the National Sudden Infant Death Syndrome center is www.sidscenter.org. Telephone: (703) 821-8955. A pediatrician's office will be aware of any supports in your community.

For loved ones of victims of a violent death or suicide, community mental health centers, law enforcement family services departments, and social service departments are avenues to explore. Our program or one of our consortium partners periodically hold trauma and suicide groups and workshops.

- **Elderly people who are experiencing other losses.** The death of a loved one may trigger a series of major life changes and additional losses for older adults, including housing issues, financial problems, and loss of independence. Departments of human services or social services generally have case management services for eligible senior citizens. Area Agencies on Aging (AAA) were established in 1973 under the Older Americans Act to respond to the needs of adults sixty and over in every local community. For more information about AAAs, call the Eldercare Locator at (800) 677-1116 or visit the web site, www.n4a.org.

Be proactive in disseminating information

- **Children and teens.** The Hospices of the National Capital Region Point of Hope Grief Counseling Center places great emphasis on offering services and information for children, teens, and the important adults in their lives. We try to be proactive in disseminating information so that we will receive the calls when a bereavement emergency arises. In addition to day camps, weekend camps, support groups, holiday workshops, and individual counseling for children and teens, we speak at PTA meetings and provide education to school staff. We also have handouts available on all aspects of child and adolescent grief.

Other resources that hospice can offer include:

- Support for someone who is grieving. We pride ourselves on responding to this topic with

direct services, including seminars, handouts, and telephone support.

- Bereaved people who have social, mental health, financial, housing, and legal needs. As with some of the life problems that arise for older adults, community mental health centers and social service agencies are generally best equipped to assist with these services.

- Family members and friends who live out of state. This one is obvious: Hospices in one state refer to hospices in another state. The National Hospice and Palliative Care Organization web site, www.nhpc.org, will provide you with information about hospices in other states.

(Editor's note: You can contact Robin McMahon at rmmahon@thehospices.org if you need additional information about locating community resources for those who grieve.) ■

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Editor: **Eric Resultan**, (770) 329-9684, (eric_resultan@msn.com).

Vice President/Group Publisher: **Donald R. Johnston**, (404) 262-5439, (don.johnston@ahcpub.com).

Editorial Group Head: **Glen Harris**, (404) 262-5461, (glen.harris@ahcpub.com).

Managing Editor: **Robin Mason**, (404) 262-5517, (robin.mason@ahcpub.com).

Production Editor: **Brent Winter**.

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Editorial Questions

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

Home health patients expect less care

Elderly people receiving home care may lower their standards of acceptability for meal preparation, bathing, and housekeeping when faced with their available resources, according to a study conducted by a group of researchers from Washington University in St. Louis.

Researchers used telephone interviews and nurse clinical reports based on in-home interviews with more than 100 elderly people discharged to home care after a hospital stay. The goal was to assess how nurses and elderly patients evaluated the sufficiency of care.

Professionals rated the amount of care, in both professional and informal care situations, as less sufficient than the elderly patients did. The nurses rated care as 2.73 on a four-point scale, vs. patient ratings of 3.21. Patients rated care higher than nurses in five areas: medications, bathing, shopping, money management, and housekeeping.

The amount of formal vs. informal care had no relationship to ratings for patients. Nurses, however, rated the sufficiency of care as lower when there were higher amounts of formal care. These findings suggest that higher amounts of formal care that are used to replace informal care cannot improve the quality of in-home supportive care. ▼

Pocket-sized infection control handbook available

The Home Care Handbook of Infection Control, a home care-specific quick reference, is now available from the Washington, DC-based Association for Professionals in Infection Control and Epidemiology (APIC). The comprehensive, pocket-sized reference combines the experience, insight, and tips of home care professionals and infection control professionals who are committed to patient safety and good employee health practices.

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APIC says the handbook includes common-sense solutions to many everyday home health infection control issues by offering a quick way to find answers without interrupting patient care.

Easy-to-use tables and charts, references, and clinical decision-making guides, as well as quick references for the management of specific infectious diseases and occupational health exposure issues, can help home care clinicians improve outcomes and patient safety. The handbook was developed jointly by the Missouri Alliance for Home Care and APIC. It is available to APIC members for \$29 and to non-members for \$38. To order, contact APIC at 1275 K St. N.W., Suite 1000, Washington, DC 20005-4006. Telephone: (202) 789-1890. Fax: (202) 789-1899. Web site: www.apic.org. ■

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