

FINDING YOUR WAY

COPING TIPS

If you find yourself diagnosed with a life-threatening illness, you can ask for palliative — or comfort — care at any point in your treatment to get the best quality of life. And, experts recommend, the sooner the better.

“(Palliative care) does not have to be reserved for the last weeks or the last months of life,” said Ronald Schonwetter, chairman of the American Board of Hospice and Palliative Medicine and professor at the University of South Florida College of Medicine.

Your doctor can provide palliative care or, in some instances, may refer you to a specialist or palliative-care team, available in many hospitals.

Remember: Asking for palliative care doesn't mean you're giving up on efforts to prolong your life. What you will be doing is recognizing that your psychological, social and spiritual needs are just as important as treating your disease.

Here are some other tips:

Recognize that pain is not an unavoidable part of the disease. It nearly always can be controlled with medicines or more sophisticated treatments.



Understand that narcotics offer the best treatment for pain for most people. Don't be afraid to use them or other strong medicines. When used appropriately, these drugs are safe, rarely cause problems with addiction and can work for as long as you need them. Your doctor should explain how to use them safely and effectively. Don't hesitate to ask for a referral to another doctor if yours is unable or unwilling to help.



Appoint a health-care surrogate as soon as you can. Choose a family member or a friend, but it should be someone you can count on to make your wishes for treatment known should you become incapable of making them yourself. Discuss your options and how you want them handled before there is a crisis. For example, would you want to be put on life support to be kept alive?

—Russell K. Portenoy

WEB SITES

**American Board of Hospice and Palliative Medicine**, 9200 Daleview Court, Silver Spring, Md. 20901; (301) 439-8001; www.abhpm.org



**National Hospice and Palliative Care Organization/National Hospice Foundation**, 1700 Diagonal Road, Suite 300, Alexandria, Va. 22314; (703) 243-5900; www.nhpc.org



**American Medical Association**, Institute for Ethics, EPEC (Education for Physicians on End of Life Care Project), 515 N. State St., Chicago, Ill. 60610; (312) 464-4979; www.ama-assn.org



**Treating Body, Mind and Spirit**, www.medicbroadcast.com/health\_topics/death\_dying/



**Palliative Care Corner**, www.painconsult.com and Palliative Care Overview



**The Center to Advance Palliative Care**, Mount Sinai Hospital, One Gustave L. Levy Place, Box 1070, New York, N.Y. 10029-6547; www.capcrsm.org

BOOKS

“**The Dying Process: Patients' Experiences of Palliative Care**,” by Julia Lawton (Routledge, 2000; \$24.99).



“**Living With Dying: A Guide for Palliative Care**,” by Cicely M. Saunders, Mary Baines and Robert Dunlop (Oxford University Press, 1995; \$23.95).



“**Hospice and Palliative Care**,” by Virginia F. Sendor and Patrice M. O'Connor (Scarecrow Press, 1997; \$39.50).



For more resources, go online to [www.findingourway.net](http://www.findingourway.net)

ABOUT THE AUTHOR

Dr. Russell K. Portenoy is chairman, department of pain medicine and palliative care, Beth Israel Medical Center, and professor of neurology, Albert Einstein College of Medicine. He is a trustee of the American Board of Hospice and Palliative Care, past president of the American Pain Society and secretary of the International Association for the Study of Pain. Portenoy is editor-in-chief of the *Journal of Pain and Symptom Management*, and author or editor of 12 books and more than 350 papers devoted to the fields of pain management, symptom assessment, opioid pharmacology and palliative care.



# Easing the journey

## Personalized care offers comfort to ailing patients and families

BY RUSSELL K. PORTENOY

**L**ike most Americans, Madeleine Corbett and her husband, John Meneghello, had no idea what the term “palliative care” meant. And like most Americans, they found out only when critical illness struck.

In September 1999, Corbett developed a hacking cough that led to a diagnosis of lung cancer. She was only 56 and otherwise healthy, and she wanted to fight hard. So her oncologist at the Beth Israel Medical Center in New York treated her aggressively with radiation and chemotherapy. Soon after the diagnosis, Madeleine's cough became so severe that her oncologist called in a palliative care specialist in the hospital's Department of Pain Medicine and Palliative Care.

Palliative care describes health care that tries to relieve pain and suffering for patients with life-threatening illnesses while giving them and their loved ones information and support.

“Palliative care is essential for all patients living with a life-threatening illness,” said Dr. Lauren Shaiova, specialist in the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center. “They and their families need a type of care that helps them have a good quality of life for as long as the disease continues, and also prepares them for the inevitability of death.”

Typically, the palliative care specialist works with a specially trained team that includes a doctor, nurse, social worker and chaplain. Often pharmacists or rehabilitation specialists become involved.

For the year and a half that Madeleine lived with the disease, her doctor and palliative care team worked together to help with one distressing problem after another.

“We've had people, doctors, tell us it's just a cancer, there's nothing we can do,” Corbett said several months before she died. “(But) there is no reason for you to be in pain. I don't want to know that six months down the road ... I'm going to die miserably. ... Most of this whole thing is the quality of life I want.”

According to government statistics, most of the 2.5 million people who die annually in the United States have incurable diseases, such as cancer, AIDS, or diseases of the heart, lungs, liver, kidneys or nervous system. Most deaths follow long illnesses, extending over weeks, months or years, leaving a lot of time for pain, emotional upheaval, isolation and spiritual distress that rob any joy from the last days.

It's a situation the health-care system is just beginning to recognize. Although palliative care is well established in many other countries, most of the American public and many professionals still know little about it. As a result, few patients are requesting it and most institutions are not equipped to provide it.

Good palliative care not only relieves pain and other symptoms and offers practical assistance for patients and caregivers at home, it encourages discussion about values and decisions in planning for medical care, and respects these decisions after they are made. And, at the end of life, it offers opportunities for closure — even

growth — and helps the bereaved deal with loss.

That's what John Meneghello experienced as he helped nurse his wife through her illness.

“The doctor was able to control her coughing,” he said. “There was really no pain. We were able right up to the end to go out to dinner, take strolls, go to a movie once in a while. She was able to do a lot of things, which were wonderful. She got closer to her brothers.”

To achieve this, symptom control is critical. Corbett's cough, chest pain, shortness of breath and fatigue were lessened by a sophisticated mix of medicines.

And just as important, the team was willing to talk about dying while helping Corbett continue living.

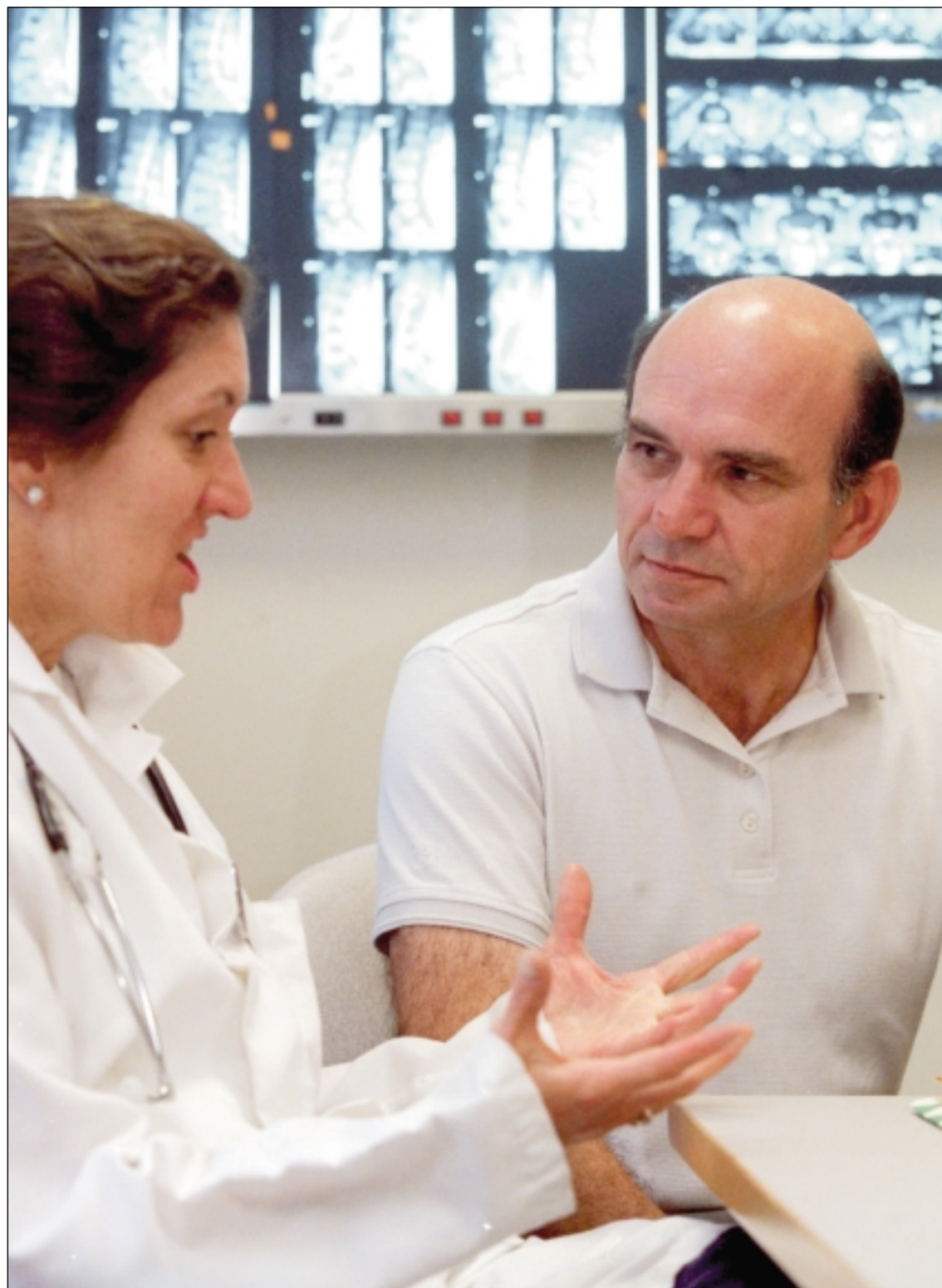
When a difficult decision had to be made about whether to proceed with a second course of brain radiation to treat the spread of the cancer, Corbett had candid conversations with her physician that allowed her to weigh the disadvantages — the possibility of more fatigue, nausea and headaches — against quality time with her husband. She decided against it.

For some patients, knowing a disease is incurable drives a need to talk about the end of life, to express hopes and fears, consider religious or existential issues or think about ways of helping their families or contributing something lasting.

Studies have shown that most doctors have difficulty with this communication. A training program in palliative care developed by the American Medical Association, Education of Physicians in End of Life Care, spends as much time teaching communication skills as symptom control. A similar training program for nurses now is being developed.

The medical profession is slowly getting on board in other ways. The American Board of Hospice and Palliative Medicine was established more than six years ago to set standards for specialist physician training and certification. To be certified, a doctor must have broad experience in caring for dying patients and pass a test that evaluates knowledge of symptom control, communication and ethics. More than 800 doctors are now certified.

Soon, experts say, this medical discipline will have standing like any other specialty, a situation that now exists in the United Kingdom, Australia and several other countries. Recognizing the need for change, many hospitals are now establishing specialist palliative care consultation teams. According to a 1999 survey by the



As part of the palliative care team at New York's Beth Israel Hospital, Dr. Laura Shaiova provided guidance to John Meneghello during the 18 months his wife, Madeleine Corbett, struggled with lung cancer.

American Hospital Association, 20 percent of hospitals now have some type of specialized service to help patients and families with end-of-life care.

Experts agree that progress will be slow. Finding a primary doctor who understands the principles of palliative care is key. This has been particularly important for Joan Beerman, an independent, 54-year-old woman who has been living with advanced cancer for more than six years. “I want my doctors to be focused on quality of

life ... (I want) my values respected and ... consideration for my family.”

Palliative care specialists encourage all patients to talk about the kind of care they want and plan for the possibility that health decisions will be needed most when they can't speak for themselves. Corbett told her doctors that her husband, John, would make decisions about her care if she no longer could.

Experts in palliative care also emphasize the need for family support. A recent study showed about one-third of caregivers have serious unmet needs, and another noted that one-third of families lose all their savings while caring for a loved one with a serious illness. Because of this impact, palliative care takes the whole family into consideration.

The palliative care philosophy is the same one that guides hospice care, which offers care, usually at home, at the end of life. In the United States, hospice care was established almost 30 years ago, and about a decade later, Medicare and Medicaid offered reimbursements. In contrast to palliative care, patients can elect the hospice benefit only if they're not receiving aggressive, life-prolonging therapies and are certified by their physician as having fewer than six months to live. For those who

qualify, hospice can provide palliative care at home through a team of professionals and services.

Ideally, as Madeleine Corbett and John Meneghello learned, palliative care and hospice can be combined to help the patient and family throughout the course of an illness.

Soon after her diagnosis, Corbett learned about the Jacob Perlow hospice, a part of the Beth Israel palliative care program, and knew it was an option when the time was right. Three months before her death in March, Corbett entered the hospice program, remaining at home with regular visits from the hospice team. When she became weaker and the treatment became more complicated, she turned to the hospice and palliative care inpatient unit at Beth Israel, which allowed her to remain home during the last days of her life. Days later, she died comfortably, her husband at her side.

For John Meneghello, looking back on his wife's long illness three weeks after her death, expert palliative care provided “an easing of tension, an easing of what people go through.”



For more resources and contacts on end-of-life issues, go to [www.findingourway.net](http://www.findingourway.net).



Long before her death in March, Madeleine Corbett sought quality for the time she had left. “I don't want to know that six months down the road ... I'm going to die miserably,” she told her husband.

## How to get the most effective treatment for pain

BY JUNE DAHL

Here's something that should come as no surprise: The thought of dying in pain scares Americans.

Over the past 25 years, significant advances have been made in treating the pain that accompanies critical illness. And new standards from the Joint Commission on Accreditation of Healthcare Organizations require health-care facilities to assess and manage pain.

Still, much of it goes unrelieved. That's because doctors and patients both harbor concerns about addiction to pain medication, as well as its side effects. And yet numerous studies find no evidence that the medical use of narcotics for

pain control in the dying leads to addiction.

Here's how to get the most effective treatment for pain:



Patients need to talk openly and honestly to family members and caregivers about their pain.



It's essential to report where and how much you hurt, what the pain feels like and how your pain is affecting your life.



Tell your doctors and nurses what makes your pain better or worse and disclose any medicines or other treatments you have been using to get pain relief.



It's always good to write down your questions before you see your doctor because it is easy to forget something during the stress of an appointment. Better yet, take a friend or family member with you when you meet with a doctor or nurse.



Always remember that your pain can be relieved, that you won't become addicted to pain medicines and that you should never hesitate to tell your doctors and nurses about your pain.



The American Cancer Society, the American Alliance of Cancer Pain Initiatives, the Cancer Information Service of

the National Cancer Institute and the American Pain Foundation offer print and Web-based materials.



Your local hospice can help with the variety of issues faced by the critically ill.



Finally, encourage your churches and synagogues, senior citizen organizations and service clubs to host public meetings on pain management and palliative care. Contact your local hospital, long-term care facility or home health agency to suggest they sponsor public meetings on critical end-of-life care issues.



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