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# Professional Issues

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IN "THE VANISHING
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Fates' view of
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Treating death

A physician-filmmaker documents her own struggle to understand and accept the end of life, gaining insights along the way

**Howard Larkin** 

AMNEWS CORRESPONDENT

N A NATIONALLY TELEVISED DOCUMENTARY, DOCTORfilmmaker Maren Monsen, MD, confronts her fear of death and dying to better serve patients at the end of life.

"I wonder what it will be like to be a doctor who doesn't see death as the enemy," Dr. Monsen asks at the end of her documentary, "The Vanishing Line." The film was broadcast nationally this summer on the Public Broadcasting System's "Point of View" series.

In the film, Dr. Monsen chronicles her struggle with what is for many physicians one of the most profound and difficult of growth experiences: accepting a patient's death as the inevitable end of life rather than as a personal and professional failing.



DR. MONSEN

Since completing the film a year ago, Dr. Monsen, who took time off from medical school to study filmmaking, has begun to discover the answer to her question. By observing and working Continued on page 10

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## Treating death

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beside hospice workers she has found that accepting death — and the limits of her skills and training in preventing it — has deeply affected the way she relates to dying patients.

"I'm comfortable just being in the room with them. I no longer feel compelled to do something, anything, to keep them alive," says the young emergency physician, a senior research fellow at the Stanford University Center for Biomedical Ethics.

But arriving at that perspective wasn't easy or quick. Dr. Monsen spent four years producing her film. "If I had quit after three, I would not have found the answers I did."

During that time, the project progressed from a relatively abstract consideration of the ethics of end-of-life choices into an introspective quest. Dr. Monsen questioned not only her basic assumptions about medical practice, but her deepest fears of death and dying. At one point, she even questioned her ability to continue as a physician.

While primarily meant for a gener-

"Medical school had taught me how to treat disease, but I had no idea how to deal with death."

Physician-filmmaker Maren Monsen, MD

al audience, "The Vanishing Line" could play an important role in raising physicians' awareness of the possibilities for end-of-life care, says James Hallenbeck, MD, clinical associate professor of medicine at the Stanford School of Medicine and director of the hospice programs at Stanford and the Palo Alto Veterans' Administration hospital.

Dr. Monsen "reveals her own uncertainty, her own questions, which is something physicians have a hard time doing. That she does so gives permission for other physicians to question their own assumptions," Dr. Hallenbeck says "She wisely doesn't provide a lot of answers, but raises the question that something is out of balance in the way physicians are trained and approach death."

Dr. Monsen's account of her struggle begins with the first time she was called to pronounce a patient dead. It was easy; she had clear instructions and the procedure took only a few minutes.

What she wasn't prepared for was the reality of being alone with a dead body. "Medical school had taught me how to treat disease, but I had no idea how to deal with death," Dr. Monsen says in her film.

She reached what she calls a crisis point with a patient whom her team successfully resuscitated, only to find out he didn't want to be resuscitated.

After removing the ventilation

tube, with his consent, she recalls walking past the room where he lay dying alone. "I stood there wanting to go in but realized, what would I say, what would I do?"

The incident left Dr. Monsen wondering if she could continue practicing medicine.

She turned to a friend, hospice social worker Jim Brigham. Watching Brigham work with dying patients and hearing of his experience with the death of his wife of 25 years profoundly changed Dr. Monsen's view of death. "I was amazed at how he could interact with patients about death. Then I learned about his personal circumstances and it raised a lot of emotional issues."

#### Abandoning a humorous approach

ALL THIS TOOK PLACE WHILE DR. Monsen was working on "The Vanishing Line." She had previously made "Grave Words," a training film that uses what she describes as "Monty Pythonesque" humor to help physicians broach end-of-life discussions with patients. She had planned to take a similar approach with "The Vanishing Line," but changed her mind as her point of view shifted and she realized she was relying on humor to avoid her own fear of death.

Instead of the humorous footage she had shot early on, Dr. Monsen ran footage of Brigham on his rounds; talking with a man so near death he had what Dr. Hallenbeck calls "the look"; raising the issue of a living will with a young man with Lou Gehrig's disease; working through a decision to insert a feeding tube with a man who felt he still had a life to live.

Brigham's story of how he and his wife reached a decision to take her off life support — and the peace it brought after a 12-year battle with multiple sclerosis — became a central narrative.

At the moment of death Brigham experienced a sensation like holding hands with his wife and then letting her go. They had discussed and prepared for the end and when it came it was a beautiful moment, he says.

The film captures the moment with imagery of water dripping until the instant of death and a bee buzzing as Brigham anticipates it. "I was really pleased about how [Dr. Monsen] did that. That's a hard thing to do, capturing the moment of death, the moment of transpersonal realization."

It's an experience that typically excludes physicians, Brigham says. "Physicians float in and out of the

#### TO GET THE FILM

"The Vanishing Line" is available from First Run Icarus
Films, 153 Waverly Place, 6th
floor, New York, N.Y 10014.; (800)
876-1710; fax (212) 255 7923. Cost
is \$225 for institutions with public performance rights, or \$95,
plus \$10 shipping, for physicians or health workers ordering individually for home use.

### Physician, know thyself

TREATING DEATH AND DYING CAN BE AS MUCH A MATTER OF self-awareness as technical skill, says neurologist Russell Portenoy, MD, who chairs the department of pain medicine and palliative care at Beth Israel Medical Center in New York City — the only such department at an academic hospital in the United States.

"American physicians are generally unprepared for patients with special needs at the end of an advanced illness," says Dr. Portenoy, a co-principle investigator for the AMA's Education for Physicians on End-of-Life Care program, which kicks off this fall. "They bring their own expectations about dying, about how comfortable patients should be, and about spiritual issues."

But these expectations are often inadequate to meet patient needs, particularly when patients are from another culture or when the doctor has not examined his or her own attitudes toward death, Dr. Portenoy says.

"The misconceptions and biases that the doctor brings to these situations compromise care," he says. "There is a very long way to go before the American physician can address and manage these issues and become comfortable as people who are going to die and care for people who are closer to death than they are."

Many physicians are aware that they lack the ability to talk to patients about death, says James Hallenbeck, MD, clinical associate professor of medicine at the Stanford School of Medicine and director of the hospice programs at Stanford and the Palo Alto Veterans? Administration hospital. Yet many are unaware that they also lack clinical skills in palliative care, such as pain management and nausea control.

"Half of patients have moderate to severe pain in the last few days of life," Dr. Hallenbeck says. "That to me is not satisfactory."

Physicians have a duty to inform themselves about palliative care, says Linda Emmanuel, MD, PhD, the AMA's vice president for ethics. "It goes back to the Hippocratic oath. We cure when we can, and when we can't we comfort."

room, and even though they have a lot of patients die, they usually don't participate in the death. Family members will talk about the death and how it was Tove all around, but physicians rarely see that. They're fighting it rather than accepting it. Physicians are designed out of the experience."

#### An ancient perspective

WHATEVER INNATE FEAR OF death Dr. Monsen brought with her was strongly reinforced by her medical training. "Our culture teaches us that we must use anything that has been invented to save lives." But her experience led her to wonder whether she was merely prolonging death.

In "The Vanishing Line," Dr. Monsen contrasts the do-everything perspective of modern medicine—shared to a large degree by American society— with that of the ancient Greeks, as personified in the mythical figures of the three fates. One fate spins the thread of life, the second marks how long the thread will be and the third cuts the thread.

The fates serve not only as an intellectual foil, but also as a unifying image for the film. They appear repeatedly; knitting in a waiting room, striding through a construction site wearing hard-hats, hovering at the bedside of a dying woman, and as shadows walking out the door at the moment of death.

"The Greek myth of fate is that life has already been measured, it is just waiting for the cut," Dr. Monsen says. "It's quite different from the biomedical model of control."

Dr. Monsen reflects that much of the work she and her colleagues do to resuscitate patients is ultimately futile. Only about 4% of resuscitated patients survive to discharge, she notes. "We need to ask more questions about when we use the technology."

But, Dr. Monsen learned through her hospice experience, there is a place for the activist role of the physician in treating death. "Trealized that even though there were no more treatments I could give to cure a patient, there were still things I could do for them."

Treating symptoms such as nausea and pain is one thing physicians can do. Acknowledging the profound spiritual dimension of impending death and talking with patients about what they want to do with the time they have left is another. Letting patients know what to expect is a third.

These options go well beyond what many physicians have seen as the limits of their skills. "Once its clear there are no more treatments, the doctor says, "There's no more we can do.' That's very disheartening for the patient," Dr. Monsen says.

It's also tough on the physician, Dr. Hallenbeck says. "If you don't have tools, including psychological tools, to deal with death, physicians can suffer a lot. If a doctor has to go in and tell someone, 'Sir, you are dying, and there is not a damn thing I can do, so good-bye,' the patient is going to suffer and you are going to suffer. You are going to be much more confident if you realize there is some care you can give."

That's been Dr. Monsen's experience. "If physicians were trained to realize what they can provide, I think they would enjoy doing it."

She hopes her film will help others come to terms with death as it has helped her. "I think that our society is one of the few that thinks of death as if it were an option. I hope that "The Vanishing Line" can help people see death as a more beautiful thing, as a more positive thing." \*