

SOLACE AT NIGHTFALL

Early in his medical career, it occurred to George Drake '69, M.D., that he had never seen a natural death. Even terminally ill patients on the verge of death were sent to the hospital to be hooked up to machines for one last effort to prolong their lives. Often they died in pain and without a loved one by their side.

"To be a witness to someone who died naturally without that kind of intervention was rare," Drake recalls.

So when the opportunity arose in his private practice, Drake made it a point to sit with patients who were dying without intervention to see what a natural death was like. "I began to believe that as a society we needed a better way of looking at death," he says. Decades later, a better way knocked on his door. While dining in a friend's home, Drake met Linda Beushausen, then vice president of administration of Hospice at Home, a nonprofit regional hospice based in St. Joseph, Michigan. They talked about how the hospice movement was beginning to change the way people view and experience death.

"She piqued my curiosity," Drake recalls, "and I decided to get involved."

Today Drake is the medical director of Hospice at Home, and he cares for dying patients on a daily basis. While that may seem depressing, hospice work is surprisingly uplifting, he says. To help someone truly live until they die, to give the patient and family members comfort and peace and help them make the most of the time they have left, is "fascinating, challenging and fulfilling work."

When a patient enters hospice care, the focus of energy shifts from the disease to the person, and how to make that person's remaining days or months as meaningful and comfortable as possible. Most patients are cared for in the place they call "home"—a private residence, nursing home, or residential facility. Because hospice recognizes the human side of suffering, the entire family, not just the patient, becomes the focus of care.

"Hospice is a holistic concept, meaning we're not only treating physical pain, but also the emotional, social and spiritual pain," says Drake. That can mean everything from addressing fears and anxieties to helping the family reconcile long-damaged relationships.

Hospice care is provided by an interdisciplinary team of trained professionals, typically a physician, nurse, a social worker, hospice aides, and a spiritual counselor, among others. The individual needs of the patient and family determine which team members visit the home and how often. Frequency can range from weekly visits to around-the-clock care. Anyone who is expected to live less than six months can seek out hospice services.

And more and more are doing so. Roughly 1.4 million Americans—or one in every three of the nation's dying—received hospice care in 2007. That number is expected to mushroom as baby boomers age and seek a better way to die.

It's just before 9 a.m. when Dr. George Drake pulls into a driveway along Route 51 in the small farming community of Dowagiac, Mich. Drake is making a house call, one of several he will have made by week's end. The 61-year-old patient living in this home, Jerry, has prostate cancer and has been under Drake's care for five months.

On this late autumn morning, the physician and Cathy Duryee, a Hospice at Home registered nurse, settle into the living room with Jerry, his wife, Glenda, and two adult sons. Jerry admits that he "overdid it" yesterday and is paying the price today. Accustomed to being active, he finds it challenging to give in to his cancer by slowing down. "I like to mow my own lawn," he says. "I like to golf. I had been golfing up to a week or so ago. I miss that."

His cancer has metastasized to his bones, causing pain in his pelvis, legs and lower back. A fentanyl patch continuously delivers pain medication through his skin, and, when needed, Jerry takes morphine to relieve breakthrough pain. He also takes medications for nausea and agitation.

Drake offers several options for bringing Jerry's pain under better control, and various family members give



DR. GEORGE DRAKE
(RIGHT) AND JERRY



input. In the comfort of their home, they troubleshoot Jerry's sleep difficulties and loss of appetite.

Later, Glenda says she's grateful that Cathy lets her know what Jerry really needs. "He's not honest with us. He's always been a very active person and he wants to stay that way, and he'll tell me at times that he feels better than he does."

Launched 28 years ago, Hospice at Home has grown from a small, all-volunteer organization to one of the largest hospices in Michigan with a daily average patient caseload of more than 170 patients and a workforce of 160 employees.

When not providing direct patient care, Drake helps to develop plans of care for patients, reviews patient eligibility for

admission, educates hospice staff, attends management meetings, and makes sure the hospice abides by Medicare rules and regulations. He stays in contact with hospice nurses—often into the night—answering their questions about patient care, discussing treatment alternatives, and approving medications.

"A lot of communicating goes on between the nurses and the families and the medical directors," Drake points out.

Conversations often lead to modifications or an expansion of care. If a patient has begun losing mobility, for example, the nurse might arrange for a physical therapy consultation to help him or her develop a new way of moving around. If family caregivers need assistance or respite, home health aides will be called in to bathe, dress, and feed the patient. Volunteers are often called upon to

provide a variety of physical and emotional comforts, from running errands to offering companionship.

The medical director and nurse might decide to use complementary therapies as adjuncts to conventional care. While massage is the most frequently requested therapy for symptom relief and relaxation, staff and volunteers also use aromatherapy. For patients feeling depressed or lonely, a visit by a trained pet can create a sense of comfort and connection.

According to Beushausen, who is now chief executive officer, music therapy has worked wonders to help soothe patients.

It may be provided live—volunteers sing or play the guitar in the home—on CD. Hospice at Home also recently formed a Threshold Choir, a group of community and staff volunteers who sing a *cappella* to patients at bedside.

Hospice work is considered one of the most demanding fields in health care. While the rewards can be many, so are the emotional challenges of interacting with dying and grief every day. Hospice at Home makes the training and nurturing of team members as important as patient care. All new team members, including volunteers, undergo eight weeks of training. Training for clinical staff goes even beyond that.

“It’s a long and intense process, but when we send them out to see patients, we need to feel they’re ready to deal with people who are dying,” Drake explains. “Even if they’ve been exposed to death in a hospital or nursing facility setting, in hospice it’s more intense because it happens all the time.”

Because feelings of loss and grief among staff are inevitable, weekly team meetings include bereavement time for sharing emotions. A small memorial service gives team members an opportunity to honor patients who died during the past week and to process their losses.

“People can light a candle, and we all say something about the person we’d been taking care of,” Drake says. “Sometimes we read poetry, sometimes people sing. It’s very ad lib, but it’s wonderful. And very necessary.”

Cathy Duryee’s phone number is prominently displayed in nearly every room of Jerry and Glenda’s house. Knowing that their hospice nurse is just a phone call away gives family members a sense of comfort and reassurance that they are being cared for. “How many people can pick up a phone and get help right away?” Glenda asks.

“I’m a worrywart,” says Jerry’s son Gus. “If I didn’t have Cathy or someone else to call with questions, I’d probably have (Jerry) in the



AT HOME IN HIS LIVING ROOM, JERRY IS FLANKED BY DURYEE AND DRAKE.

hospital or doctor’s office every day.”

Jerry had had a particularly scary day the previous Sunday—“a wipe-out,” he calls it. He was confused, forgetful and clumsy, generally in a daze. Knowing that Cathy was due to visit the next morning and knowing they could reach an on-call nurse any time of night if Jerry’s condition worsened, the family never had to consider running Jerry to a hospital emergency room.

“If we didn’t have hospice,” says Glenda, “our lives would be so much more chaotic.”

“One of the most important things we do is listen,” Drake said. “When talking to a person who is dying, you want to know what pain they’re having and to find out about their suffering—their emotional, spiritual suffering. If you listen carefully, you hear hints about what else is going on in their lives.”

Drake began listening, *really* listening, while a student at Kalamazoo College. The school’s rigorous academics and emphasis on critical thinking forced him to learn how to listen closely and think about what people were saying. He grew to love hearing other people’s stories.

But later, as a physician in private practice, he found that listening can be a liability as well as an asset.

“Because I would take the time to listen to my patients, to learn about them as people, I had trouble keeping my doors open as a business,” he recalls. “Primary care in this country in the past decade or two has been all about volume. If you’re going to be successful, you have to see 30 or 40 patients a day. It’s hard to get to know somebody when you’re seeing them for five or 10 minutes. Medicine becomes piecemeal, and that’s alien to me. It’s not who I am or who I want to be.”

Hospice at Home makes listening a priority, not just for medical directors, but for the entire hospice team. Hospice aides, in particular, are likely to hear telling information they can bring back to the team.

“Because they’re involved in such intimate, personal care of the patient, that relationship gets very close,” Drake explains. “Things get revealed, and when it comes back to the team, those with the appropriate expertise—psychology, spirituality—can intervene. That’s the wonder of working as a team.”

Accepting an illness as terminal brings about a sea of emotions. For Jerry, feelings of guilt and anxiety are at the forefront. He feels guilty about being a burden on his wife and children and worries about

the effect his death will have on them. He feels guilty, too, about Duryee having to come to his house to check on him.

“Like he’s a burden on me,” Duryee says. “He says, ‘You have other people who are worse; you need to see them, not me.’”

It’s difficult to give your care over to other people, when once you could do it on your own.

“Between my wife and the kids and hospice, it’s been pretty much a full-time job,” Jerry says.

Glenda’s emotions are in check for now. She says it’s not about her at this point: “I’m not ready to go there. I have to stay strong.”

Cathy reminds Jerry and Glenda and sons Eric and Gus that counseling is available if they want it; all they have to do is ask.

A 2007 study by Duke University concluded that hospice care is one of the few health care services that improves quality of life while saving money. Yet with everything that hospice care offers, it has been vastly underutilized. According to the National Hospice and Palliative Care Organization, for every person who receives hospice care, there is another person who is eligible but doesn’t seek it out.

Cost is generally not the issue; hospice care is covered under Medicare, Medicaid and most private insurance plans, and grants and community donations provide additional support so

that patients can receive care regardless of their ability to pay. A primary cause of underutilization is the unwillingness of patients and physicians to accept the reality that the patient cannot be cured, Drake says. Physicians are trained to do everything possible to prolong life, and even when they recognize that treatment is futile, most feel uncomfortable delivering the bad news to patients and their families.

Drake expects that to change now that palliative care is becoming a recognized subspecialty in medicine and more patients are realizing they can take control of their end-of-life care. Baby boomers see how their parents are dying and want a better way.

“Whereas the previous generation followed doctors’ orders without asking questions, we now have a more educated, internet-trained generation of people who know what they want and what they can have,” Drake explains.

Drake has a favorite quote about doctoring. In a lecture delivered to Harvard students in 1929, Dr. Francis Peabody said, “The secret of the care of the patient is in caring for the patient.” Since that lecture, generations of medical students have learned those words; Drake feels fortunate to be able to live them.

“Sometimes it feels like a dream, to be able to make such a difference in people’s lives, at this time in their lives,” he says. “I’m where I’m supposed to be. I really feel that deeply.”

Debra Dew, R.N., a case manager for Hospice at Home and a close colleague of Dr. George Drake '69, happens to be the sister of Kalamazoo College Writer-in-Residence Diane Seuss '78. Seuss wrote a poem about her sister's work. Dew shared it with Drake, who often reads it aloud at various gatherings.

CHANGES INSIDE

Do you feel something changing inside you? *I don't know, baby.*

She unwound the wet sheets from his legs, his feet and hands gone lilac, moving in the direction of morning glory, and then, well,

night sky, close to night sky. Catheterized him. I don't know this man, only heard tell of him. Earlier, she'd drained liters of fluid

from his liver. Not unusual, the oceans a body can hold. And who wants to admit that inside the tides have shifted, have receded

or tumbled ashore? Who can own up to the iridescence, the urchins and bones and stars inside us, to the wind shift,

the sailing ships shifting course? *I don't know*, he says, but he knows, and he calls her, his strange nurse, *baby*, for every dying

sailor sees a mermaid off the prow, and every man must confess to beauty as he goes, to this woman who brings opiates

in gloves the color of snow.