

Teaching doctors to help heal when death is near
UW medical course focuses on limiting pain and anguish in a patient's final days

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On a rainy, dreary December day, Nathan Marsh is visiting a dying man and his wife at their home on a narrow street overlooking Lake Washington.

With a social worker from Providence Hospice of Seattle as his instructor, Marsh, a fourth-year medical student, is there to learn a skill most doctors haven't honed -- how to guide someone through the end of their life with minimal pain and anguish.



 Meryl Schenker / P-I

As part of a new UW medical course on caring for patients facing death, Nathan Marsh, right, interviews cancer patient J. Kyle Dietrich, 73.

The man they've come to see, Albert Mortinson, a retired salesman for an envelope company, has lung cancer. A series of strokes make swallowing difficult. He is 81 years old. He has been in hospice care since July.

Twisting a rubber band between her fingers, Hazel Mortinson waits out her husband's coughing fit. "Oh my goodness. Oh my goodness," she repeats to no one in particular.

Marsh stands back, absorbing the scene, trying not to intrude.

He's part of a new program at the University of Washington Medical School that is introducing doctors-in-training to a realm of medicine devoid of cures, where wins are measured instead in the quiet realization of peace and acceptance.

Marsh is not with the Mortinsons to provide treatment. He's there to observe how professionals who deal with death every day tease out a patient's fears, assess their pain and tend to their family's concerns.

The training is designed to help Marsh build relationships with his own future patients who are faced with a time when life-prolonging measures are no longer possible or desired.

At a lanky 6-foot-2, Marsh towers over the Mortinsons. Hazel, 83, always a small woman, has been shrinking with age. Her slight figure barely comes up to Marsh's chest.

Taking advantage of the tall young man in her house, Hazel puts Marsh to work winding a clock over the mantle.

There's some discussion about the nebulizer that helps Albert breathe easier and a gentle suggestion from social worker Rusty Myers that the couple consider Meals on Wheels to relieve Hazel's workload.

Hazel doesn't think she needs help.

"Do you quit the way you've done business for 40 years?" asks Albert. "It's kind of hard to get used to."

It's a difficult time for the caregiver as well as the patient.

"You feel like you're a bubble popper," said Myers. "They have this fragile little belief and you don't want to steal their greatest hope."

Talking about death

Palliative care is a specialty that concentrates on providing physical, emotional and spiritual comfort for patients with life-threatening illnesses.



 Meryl Schenker / P-I

Al Mortinson, 81, who has lung cancer, visits with social worker Rusty Myers while UW fourth-year medical student Nathan Marsh observes as part of his palliative care course. Family friend Vanessa Adamson is in the background.

The four-week UW course in palliative care, for Marsh sandwiched between radiology and a stint in the intensive care unit, is nothing like his other rotations. It requires more listening, less doing.

Marsh, who likes the hands-on approach of a surgeon's work, wants to go into orthopedics because "it's more (about) rebuilding than cutting something out." In his chosen specialty, he won't often be treating dying patients.

But a stay with an older cousin with terminal cancer last summer in California convinced him to take a course in palliative care, a relatively new but growing area of study at medical schools nationwide. Marsh suspected his cousin, a physician himself, wasn't communicating with his own doctor.

"He was in a lot more pain than he needed to be."

His cousin's experience raised a whole new set of questions for the would-be doctor about how to communicate with patients who are dying.

"I'm definitely not a pro at having those sorts of conversations with people," Marsh said.

Talking about death -- even with a patient who is speeding toward it -- is difficult for many doctors, said Dr. J. Randall Curtis, director of The End of Life Care Research Program at Harborview Medical Center.

In a study published earlier this year in the European Respiratory Journal, patients with advanced lung disease said their doctors never initiated conversations about what dying would be like, how long they could expect to live or their spiritual beliefs.

"If we're going to improve the quality of care for people around the end of life, we have to talk to them about it," Curtis said.

Learning how to listen

Nearly two decades ago, Dr. Stuart Farber indulged in a smug moment of professional satisfaction while walking to the hospital parking lot.

He'd just finished meeting with a patient, an elderly woman dying of an especially painful type of cancer.

Farber carefully explained her treatment options, including an experimental procedure that would involve amputating her leg and part of her pelvis.

He wanted the woman to have all the information she needed to choose wisely.

She told him she was in her 70s and not interested in a radical, disfiguring operation. She'd rather die at home.

"I thought I was being this wonderful, caring doctor," Farber said.

Then, his pager went off. His patient had attempted to jump out of a sixth-story window.

"You haven't been listening to me," the patient told him when he returned to her room. "I'd rather be dead than live with this pain. Can you help me?"

She was immediately admitted to the hospital, where high doses of pain medication kept her comfortable. A few days later, she died.

Farber, an associate professor of family medicine at the UW who helped design the school's palliative care course, said he wants medical students to know how to listen before they begin treating patients on their own.

"I felt like I had failed this woman and I didn't even know it," Farber said. "I didn't know anything about her situation or her story."

Using medicine to soothe

Often, palliative care is delayed until death is imminent, leaving people with chronic illnesses to suffer while there's still hope for recovery.

Medicare won't pay for hospice care until a patient is expected to die within six months. And after patients switch to the hospice care benefit, Medicare no longer covers treatments related to their terminal illness, according to the Medicare Rights Center, a national, non-profit group that offers advice and information about Medicare benefits.

The Medicare rule tends to divide doctors from those who care for the dying, including non-physicians, said Dr. Ira Byock, director of palliative medicine at Dartmouth-Hitchcock Medical Center in New Hampshire.

"The traditional model ... is we treat the disease as hard as we can ... until little if anything more can be done," Byock said. "Then we say we'll send you to hospice care where you can really be nurtured and your symptoms expertly managed."

About one in five U.S. hospitals now has an in-house palliative care program, an increase of 42 percent in the past two years, according to the Center to Advance Palliative Care.

Their emergence marks not just a more open culture around death, but a recognition that medical advances should and can be used to soothe as well as cure.

For example, by injecting a numbing medication into a nerve, doctors can relieve the intense pain of pancreatic cancer.

"It can transform somebody who has been suffering from terrible pain into somebody who can enjoy life," said Dr. Susan Block, co-director of the Harvard Medical School Center for Palliative Care.

Chemotherapy can also be used to shrink a large tumor and relieve symptoms, even if it's not expected to ultimately beat the cancer, said Block.

"What's important is that we don't think of it as being an either/or -- either you treat the disease or give up hope and just treat the symptoms," said Block. "I think about palliative care beginning at the time of diagnosis of a life-threatening illness."

Still, there's evidence of a lingering intransigence in medical training, said Block.

Students at Harvard Medical School almost never work with terminal patients, according to a study published last year.

"The residents (either) said this patient is too complicated for medical students or this patient is dying so there's nothing to learn."

When death is imminent

On another hospice call, Marsh meets an elderly Russian woman struggling with a severe bout of angina in the tidy apartment she shares with her daughter.

One wall of the small living room is lined with glass cases filled with rows of old, hardback books. A picture of the younger woman's husband, who died before the family moved to the United States 11 years ago, sits on a shelf.

The daughter is 70, the mother 97. (The women asked that their names not be used.)

The older woman, dressed in a skirt and sweater, sits in a chair with her back to a sliding glass door that opens to a small balcony.

"This is my babushka," says nurse Beverly Fletcher, using the Russian word for grandma.

The family has decided the time for extreme, life-prolonging measures has passed.

"It's always like this -- sudden and very bad," says the daughter as her mother's breath grows raspy and she complains of head and chest pain.

"She's a DNR (Do Not Resuscitate) so she's all right," says Fletcher. She guides the older woman to the couch, puts nitroglycerin tablets under her tongue, hooks up her oxygen, and gives her some pain medicine. "We're just going to give her some comfort."

Watching a woman with heart disease have an attack without calling 911 is tough for Marsh. "With a hospice patient, I didn't know. What do we do? How

much treatment do we give?"

For many doctors, forgoing life-saving treatments can leave them with a sense of failure.

"We can keep people going with a chronic debilitating disease," Farber said. "People live longer but they may be living the life they fear the most."

For his part, Marsh said he's always aspired to do more as a doctor than put people back together again.

"You want to fix those things because you think if people are healthy they'll have a more fulfilling life.

"When you get to the end of life and you don't have those life-prolonging things to do anymore, how do you help people find healing?"