

BRINGING COMFORT

TO PAIN AND
PASSAGE

PALLIATIVE CARE
EASES

THE SUFFERING OF
SERIOUSLY ILL
PATIENTS
AND
THEIR
FAMILIES.

BY WHITLEY HILL

“Why is my wife on a ventilator?” asked the man in the emergency room. “Because her cancer has gotten worse,” replied Adam Marks, M.D. “What cancer?” asked the man.

“The lung cancer she was diagnosed with several months ago...” said Marks, surprised by the question.

“Oh no,” said the man. “God came to me in a dream and told me to lay hands on her and I did and she is cured of her cancer.”

Marks pauses as he recalls what happened that day in the University of Michigan Intensive Care Unit on one of his very first days as a resident. The young doctor looked up the woman’s record. Several months before, she had been diagnosed with metastatic lung cancer. She had been offered chemotherapy with the understanding that it probably wouldn’t cure her disease, but might add a few months to her life; she had declined. Now she was back in the ER unable to breathe. And Marks was in the midst of an impossibly difficult conversation.

But he wasn’t particularly surprised. Throughout his schooling Marks had noticed a disturbing disconnect in the way physicians and patients talked – or, rather, didn’t talk – about death and suffering. Again and again, he’d witnessed people with a life-limiting disease who were surprised to learn that their disease was, in fact, life-limiting.

Because of this misunderstanding, they and their families were being forced into untenable positions. There was suffering, fear and panic. Late-night trips to the ER. People were receiving painful, pointless interventions and dying in the intensive care unit – instead of peacefully in their homes. All because of a failure to communicate. Now, Marks was face-to-face with just such a situation, unsure how to proceed.

“I thought, ‘This is going to be a disaster. This is going to be faith versus science and this poor woman will be stuck in the middle and she’s going to die a terrible death and there’s going to be anger all around.’”

Instead, a group of doctors trained in palliative care was summoned to meet with the family. Marks watched as an unexpected miracle took place.

“They said, ‘As doctors of science, we can’t comment on matters of faith but what we can comment on is that your wife is dying and it is beyond our ability, as mortal hands, to heal that.’ And he got it,” he recalls.

Soon, the woman’s family gathered around her bed. They prayed as the ventilator was removed and she died a peace-

ful, calm death.

What happened next changed the course of Marks’ career. “The husband came around and hugged each one of us. It really drove home the power that this kind of care can have for somebody. I completed my residency, then applied for a fellowship in palliative care and here I am.”

Today, Marks is an attending physician who works in adult and pediatric palliative care in both inpatient and outpatient environments. He’s part of the University of Michigan Health System’s new Adult Palliative Medicine (APM) program, an initiative that positions the institution as a national leader in the emerging field of palliative medicine.

Those who have devoted their lives to the field feel passionate about defining it, particularly in the face of recent efforts to politicize their work. Terms like “death panels” and “rationing” horrified palliative care specialists across the nation. In fact, the field is so broad yet so nuanced, it can be confusing to pin down.

“I have senior doctors asking me the difference between palliative care and hospice, for example,” says Raymond Yung, M.B., Ch.B., chief of the Division of Geriatric and Palliative Medicine. “Some people mistakenly believe that palliative care is only for patients who are incurably ill; our goal is to provide relief from the symptoms and stress of a serious illness – whatever the diagnosis.”

That, adds Yung, means aggressively addressing all aspects of a patient’s suffering: pain, nausea, diarrhea, agitation, anxiety, depression, even when – especially when – it is clear that a cure is no longer possible. And it means doing so in a manner aligned with their faith, beliefs and values.

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To that end, the new APM program — built on more than 10 years of committed work by concerned physicians from all specialties, as well as nurses, social workers, spiritual care workers and administrators — is making a quiet but profound difference in the way medicine is practiced at the U-M. Since 2005, the APM consult service has met daily to confer honestly, compassionately and creatively about some of the sickest patients in the hospital. The service's interdisciplinary team has worked with over 5,000 such patients, some of whom are clearly dying, others just overwhelmed by suffering and confusion about their diagnosis and options. When called upon by a patient's primary physician — or, increasingly, by patients and their families — the team visits patients in their rooms to listen to their needs, to plan and to help.

For patients near the end of life, the goal of those conversations is to understand a patient's preference, says Marks.

"I've had people say, 'It's important to me to feel as if I have fought for every day with my family. I need to know that I have done everything in my power to stay on earth as long as possible.' It's quantity, not quality," he says. "And they need to be 'full code' and their death needs to happen in the ICU, and that's our job. Any limits to care will be the limits of futility. We wouldn't offer a heart transplant or a lung transplant if it would be of no benefit."

He adds that being part of a large and world-renowned medical institution means that patients often come here expecting to be cured after other hospitals have "failed."

"My job is not to take away someone's hope, but to share in that hope," he says, "and also to plan for what we expect. It's my job to tell them that. I say 'I will continue to hope with you for a cure, even if we're talking on the level of a miracle, but this is what I expect.' The research about communication is fairly limited, but we do know that people

are looking for a balance of hope and realism.”

The program also serves the outpatient clinics of the Cancer Center, the Geriatrics Center and Chelsea Family Medicine. They maintain a strong partnership with the VA Ann Arbor Healthcare System and with area hospices.

In 2010, a study conducted at Massachusetts General Hospital and published in *The New England Journal of Medicine* made an unexpected discovery. In the three-year study, 151 patients with advanced lung cancer were randomly assigned to receive either standard oncology care or a blend of standard oncology care and palliative care — pain relief and close attention to a patient’s quality of life beginning near the time of diagnosis.

The study showed that patients who received palliative care not only reported improved quality of life, they actually lived about two-and-a-half months longer than those who received only treatment for their cancer.

“The study was a breakthrough in palliative care literature. And I was not surprised at the findings,” says Marcos Montagnini, M.D. (Fellowship 1998), who has directed the Hospice and Palliative Medicine Fellowship program at the U-M since 2007 and oversees palliative medicine for seven VA hospitals, including the one in Ann Arbor. “There’s this misconception that palliative care and hospice shortens people’s lives, but it’s actually the opposite. When my patients receive good and competent palliative care, they can improve temporarily. They remain as functional as possible during their remaining time.”

Currently, three physicians per year complete U-M fellowship training in the specialty, prior to sitting for certifying exams with the American Board of Medical Specialties. Many apply after years practicing in family medicine, internal medicine, emergency medicine or other fields. They come to the specialty with a belief in its value to their patients and to medicine in general.

Each fellow starts the day visiting patients they’ve been working with, checking on pain management, addressing concerns. Then, they convene with the interdisciplinary palliative care team: physicians, nurses, social workers, pharmacists and spiritual care professionals all bound by a common goal to ease suffering.

There’s a pressing need for increased funding to train palliative care specialists, says Phil Rodgers, M.D. (Residency 1998), associate director of the fellowship program and founding director of the UMHS Palliative Care Program.

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The American Academy of Hospice and Palliative Medicine recently reported that there is currently one palliative care specialist for every 20,000 older adults living with chronic disease. Compare this to the one cardiologist who is available to care for about 70 Americans experiencing a heart attack and the disparity becomes even more startling.

“We’ve got to find the funds to train more fellows,” says Rodgers. “We need to care for patients with advanced illness in a more sustainable way. The way we’re doing it now is not sustainable.”

Montagnini says it costs about \$70,000 to support a fellowship slot for a year and is constantly searching for ways to expand the program and train new specialists.

“Without them, more and more people will be dying in hospitals with poor pain control and no attention to their emotional, social and spiritual needs,” he says.

Of course, the sad truth is that some of the patients facing chronic pain, disability and the end of life are babies and children.

Longtime Ann Arborites Ruth Schekter and Bill Zirinsky have a profound understanding of the power of pediatric palliative medicine. Their children, Samuel Ezra, born in 1994, and Juliana Fay, in 1999, were afflicted from birth with a severe neurometabolic degenerative disorder so rare it had no name and no



Phil Rodgers

treatment. Though profoundly disabled, both children lived lives filled with love, learning and joy. Sam died in 2004, Juliana in 2008. Though Schekter and Zirinsky say their family's experience at C.S. Mott Children's Hospital was "exceptional," they acknowledge there was a marked difference in the end-of-life care each child received.

Sam's final weeks were spent in the pediatric intensive care unit; there were many interventions. When it became clear that Juliana "was on the same trajectory, we didn't want her to have the same experience," Schekter says. By that time, the Pediatric Palliative Care Consultation Service was available at Mott and the family chose that option. A team of profession-

als headed by Kenneth Pituch, (M.D. 1981, Residency 1985), helped the family care for Juliana at home in her final weeks.

Recognizing the need for support of palliative medicine at Michigan, Schekter and Zirinsky made a generous gift to the program in honor of Sam and Juliana. Today, the new pediatric palliative care suite at Mott bears their names.

Pediatric and adult palliative care differ in some important ways, says Pituch, including the fact that about 80 percent of the kids they treat have never been healthy; they were born with challenging physical anomalies and their lives have been a merry-go-round of interventions large and small, effective and not, from the start. The other 20

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percent have developed life-limiting conditions like cancer, heart disease and degenerative neurological disease.

"Our expectation is not curing your child; you already have doctors who are doing their best," says Pituch. "We're here to ask what else might help. Pediatric palliative care includes care at the end of life, but also focuses on what you want your life to be as you go through your serious illness."

He adds that the comfort these children receive often seems to extend their lives. Many children who receive palliative care are still alive a year later. For those who've chosen not to be in the hospital, or who enter hospice, half live more than six months. "A significant number 'graduate' from hospice; they don't die," says Pituch. "Pediatric palliative care can go on for a long time."

Mott's first fellow in pediatric palliative medicine began training in the fall.

Raymond Yung,
Marcos Montagnini
and Adam Marks



As anyone involved this new specialty knows, a desire for money doesn't lead them here; those who devote their lives to palliative care are compensated well below many other specialties. Philanthropy will always be needed to support the training of new specialists in the field as well as new research.

"In my clinic," says Marks, "I see two or three patients an afternoon, and I'm spending an hour-and-a-half talking to each. But the Health System recognizes that this is value-added care, because we help keep people where they want to be: at home. People aren't coming to the hospital with shortness of breath – or in pain – because we're managing it better at home. This is medicine that people want – helping people live as well as they can for as long as they can."

So, there are long hours for comparatively little pay. Pain, suffering, death, grief. Why are palliative medicine doctors so passionate about their specialty? In part, it comes back to the stories they hear every day, the people they meet.

"People think it's depressing, but in fact, it's quite the opposite," says Marks. "Every day I have affirmed to me what's important in this life. Every day I hear amazing stories about family reconciliations, about redemption, about the amazing lives my patients have led. Because people are eager to tell you their stories! The families want you to know that their dad was a World War II vet, that he served in the Battle of the Bulge. I hear 'I met my wife in high school and we've been together for 60 years.' And what a beautiful story that is. It's such a blessing to work in this field." [M]

JULIANA'S STORY

In 2009, parents Ruth Schekter and Bill Zirinsky spoke at a Grand Rounds presentation at University Hospital. Below is an excerpt of their talk.

When it came to Juliana, we had been around the block once before, and we didn't want to go that way again, not for her and not for us. Most families facing critical decisions about end-of-life care for a child don't get to do it again. We did. And we wanted to do it better, if there is such a notion in the context of losing two children.

In the fall of 2007, we met with Dr. Pituch and his team. They were like a godsend for our family. They could help Juliana be comfortable over the next few months...comfort care. The whole family has been traumatized over an extended period, and our family needed for Juliana's final months to be peaceful, without the drama of Sam's final weeks, to be a gentle going forth into the night.

Parents of chronically ill children need to be heard and listened to. They are truly the experts about their own children. The Palliative Care team worked with our family in such a deeply kind and respectful way — and it made all the difference.

Juliana had a good Christmas at home, and lots of time with family and friends. Her physical therapist came over and worked with her just five days before she died.

The next day, the local therapeutic horseback riding program brought one of their ponies to our house. Juliana loved horses. It was a beautiful, cold January day, and we bundled up Juliana and took her outside to visit with that pony, whose name was Pretty Boy.

Juliana got on Pretty Boy for a little while, and she petted that pony and

smiled at that pony, and absolutely beamed as she breathed in her last rays of outdoor sunshine. That afternoon was as good as life gets.

When the next day came, she was only barely conscious. The day after that, Dr. Pituch stopped by and arranged for Juliana to have just the right oxygen mask to wear and instructed the nurse on how to carefully maintain her comfort.

The next night, Juliana's last, we very, very carefully lay her between us in a double bed that we brought into her bedroom. We held her all night long, listening to her breathing, and she was comfortably nestled between us. Our dear friend Ann chanted the holy Sanskrit chant all night long. Right at the crack of dawn, Juliana slipped away from us.