# QUALITY CARE, TO THE END

## UB ESTABLISHES DIVISION OF PALLIATIVE MEDICINE

By Nicole Peradotto

DURING HER RESIDENCY IN INTERNAL MEDICINE AT UB, AMY McDONALD, MD '01, FOUND THAT SHE WASN'T INTIMIDATED BY THE PROSPECT OF DISCUSSING DEATH AND DYING WITH TERMINALLY ILL PATIENTS. ON THE CONTRARY, SPEAKING CANDIDLY AND COMPASSIONATELY ABOUT END-OF-LIFE ISSUES, WHILE OFFERING HER PATIENTS AN OPPORTUNITY TO OPEN UP ABOUT THEIR FEARS AND WISHES, CAME NATURALLY TO HER.

Or, at least more naturally than her peers. Once they learned that she was comfortable broaching such a difficult bedside subject, McDonald's phone began to ring.

"My colleagues would call and ask me, 'Can you talk to my patient about this, too?'" she recalls.

Five years later, McDonald has parlayed her sought-after communication skills into a fulfilling career in palliative medicine. An assistant professor of medicine at UB, she runs the 20-bed palliative care unit at the Buffalo Veterans Affairs Medical Center and is director of UB's palliative medicine fellowship, one of 55 accredited programs in the country.

"People think that working in the field of hospice is depressing. My answer is, 'Not at all,'" McDonald says. "In the same way that it's rewarding for an obstetrician to bring a life into the world, it can be rewarding to help people go through the dying process. You can make a tough situation quite good for patients and their families. If you relieve pain and suffering, that's not depressing. You feel really good at the end of the day."

Until recently, the fellowship in palliative medicine, along with a popular palliative medicine elective for fourth-year medical students, existed without a formal home in the School of Medicine and Biomedical Sciences. To the delight of McDonald and other palliative care proponents, that changed last spring when UB created its own Division of Palliative Medicine within the Department of Internal Medicine.

According to division director Jack Freer, MD '75, organizing palliative medicine into a division brings recognition to both a subspecialty that is coming into its own and the faculty charged with teaching the next generation of physicians how to alleviate suffering and promote quality of life for patients nearing the end of life.

**AMY McDONALD, MD '01**

**“AS A FIELD** that has its own academic infrastructure and its own research base, palliative medicine is relatively new,” notes Freer, professor of medicine and clinical associate professor of social and preventive medicine. “There are now several journals that are reporting high-quality research, and it’s really maturing as a medical discipline, but for awhile it was just individuals in their own practices trying to come up with something that worked best for their patients. It didn’t have that identity of a coherent, cohesive medical specialty.”

### CHANGING ATTITUDES

Only three decades ago, palliative medicine was still a largely unrecognized term in medicine. That has gradually changed as deficiencies in terminal care have come to light along with a growing recognition that palliative care can contribute to more comfortable deaths while eliminating expenditures for interventions determined to be futile.

The evidence of shortcomings in end-of-life care is underscored in the oft-cited SUPPORT study, a multicenter randomized trial of 9,100 seriously ill patients that found that severe pain was common, decisions to withhold invasive treatments were made at the last minute and physicians often had no knowledge of patient preferences concerning emergency resuscitation.

When the results were published in 1995, they stunned the health-care community. According to the Robert Wood Johnson Foundation, which funded the study, the findings “pointed to a popular and medical culture that so forcefully resists the notion of death that families, health-care practitioners and patients themselves are unwilling to ask questions and make the kinds of decisions that would diminish the fear surrounding the process of dying in this country.”

Indeed, some palliative care practitioners consider the United States a society so obsessed with prolonging youth that we harbor unrealistic notions about mortality. Thanks to the myriad medical technology advances of the last century, there can be little doubt that the current generation accepts death much less willingly than its forebears.

“What could physicians do before the 20th century? They could diagnose, prognosticate, and, to some extent, soothe and comfort,” Freer says. “But they couldn’t take control of the infectious diseases the way we’ve been able to with antibiotics. So in the 20th century—particularly the second half of the 20th century—there was a sense that we could do all kinds of things to thwart death. Therefore, people who’ve grown up in the past 60 years or so don’t view death in the same way as people did in the past—as inevitable and a part of life.”

McDonald has seen how denying death’s certainty can lead to even greater distress for everyone involved. Although she is sympathetic to the heartache dying patients and their families endure over the final farewell, she knows that trying to forestall it often results in a “bad death”—the result of medical interventions that delay a patient’s passing but fail to restore quality living.

“In the olden days, people died at home. Now the attitude is: ‘Why don’t we do another test?’ or, ‘Maybe they’ll pull through,’” McDonald says. “There’s always that hope of a medical miracle, which I understand, but people want to cheat death for their loved one.

“Meanwhile their 90-year-old grandmother is lying there on a ventilator. You think, ‘When are we going to accept it and say, ‘Enough’?’”

It’s not only families who may be unwilling to let go. To physicians—who’ve been rigorously trained to assess, treat and cure—death is often viewed as a failure. That attitude may be one reason why some physicians give overly optimistic prognoses to their terminally ill patients; one study shows that physicians overestimated survival three times as often as they were accurate in their prognoses. It also helps explain why they may be enticed by therapies that contribute to the unnecessary extension of treatment while allowing them to put off critical conversations.

“It’s difficult to acknowledge that a patient is dying when your goal has been to keep them alive and fight the underlying disease,” says Freer, who teaches UB’s palliative medicine elective. “It’s an admission that nothing you’ve tried has worked. And, it’s difficult to break bad news. There are different strategies that we teach at the medical school that make it more manageable, but it’s hard to do and awfully easy to procrastinate.”

The result, according to Freer, is that patients drift further toward death before any serious discussion of palliative and hospice care takes place.

“That, I think, is the most frustrating thing,” he says. “People wind up not being able to take advantage of broader, more meaningful care at the end of their life because it’s difficult for physicians to bring up those topics and talk about them.”

### EDUCATING OTHERS

At UB, and within Western New York’s medical community, Freer is attempting to raise the profile of palliative medicine so doctors are less hesitant to initiate these conversations, and patients and their families are aware of options for comfort and care in the face of death.

To that end, he plans to establish palliative care consultation services within area hospitals that don’t have them in place.

“Palliative care has not been mainstream where people think about it immediately,” he points out. “Physicians don’t have any problem finding the specialist who they believe is going to treat the patient’s illness from a very disease-specific point of view. The more difficult problem is to get physicians to think about palliative medicine for the patients with cancer, for the patients with heart failure, for the patients with Alzheimer’s. Hopefully, with palliative medicine consultations, residents and students will see that there is this other way of caring for patients with life-limiting illnesses.”

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Beyond serving as the palliative medicine fellowship director, McDonald educates her peers about palliative care in a less formal way: by touting its benefits to other medical health professionals she encounters on the job.

“But even when I talk about it until I’m blue in the face, some people still have this idea that palliative care is giving up,” she laments. “One of my biggest pet peeves is hearing, ‘There’s nothing more we can do for you so it’s time to think about palliative care.’ To me, that’s nails on the chalkboard because there’s so much we can do.”

When McDonald feels discouraged that more of her colleagues don’t embrace palliative care, she reminds herself why she got into the field in the first place: to improve the quality

JACK FREER, MD ’75

### MILESTONES IN PALLIATIVE CARE

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| 1967 | British physician Cicely Saunders, founder of the modern hospice movement, establishes the world’s first hospice facility in London. |
| 1969 | Elisabeth Kubler-Ross publishes *On Death and Dying,* her groundbreaking book in which she proposes the now-famous “five stages of grief.” |
| 1974 | Balfour Mount, a surgical oncologist in Montreal, coins the term “palliative care.” |
| 1990 | Congress passes the federal Patient Self-Determination Act (PSDA) to encourage competent adults to complete advance directives. |
| 1995 | The landmark SUPPORT study surveys the dying experiences of more than 9,000 Americans and finds that at least half spent their final 72 hours in moderate to severe pain. |
| 1997 | With the support of the Robert Wood Johnson Foundation and George Soros’s Open Society Institute, a major effort to bring palliative care into mainstream medicine and nursing is launched. |
| 2004 | Clinical Practice Guidelines for Quality Palliative Care are released, expanding its focus to include not just dying patients but also those diagnosed with life-limiting illnesses. |
| 2006 | The American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education (ACGME) recognize the subspecialty of Hospice and Palliative Medicine. |
| 2008 | The first certification examination in palliative care is given. |

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of care for patients with advanced illness. "In my training I saw a few cases that went badly in terms of patient care, and it made me want to educate others and improve the way this care is provided," she says.

"There will always need to be education about palliative care, and there are still people dying very uncomfortably all over the country," she continues. "That's why I spend a lot of time dispelling myths about it."

If last summer's debate over health-care reform is any indication, such myths can take on a life of their own. When a provision was made in the House bill to reimburse doctors who discuss end-of-life options with patients and families, it was decried by several opponents, including former vice presidential candidate Sarah Palin, who claimed it would give rise to government "death panels" that would encourage euthanasia. Although denied, the rumors created enough controversy that the Senate Finance Committee dropped the provision from its health care bill.

## MAKING HEADWAY

That setback notwithstanding, palliative medicine has made impressive strides over the past several years. In 2006, the American Board of Medical Specialties (ABMS) approved hospice and palliative medicine as a recognized subspecialty, marking the first time 10 ABMS member boards have collaborated in the offering of certification in one specific area. The same year, the Accreditation Council for Graduate Medical Education (ACGME) approved an accreditation process for hospice and palliative medicine fellowships. UB's program is closely affiliated with the Center for Hospice and Palliative Care, and its fellows spend a substantial amount of time training at Hospice Buffalo in addition to the VA, Roswell Park Cancer Institute and Kaleida Health sites.

Since the seminal SUPPORT study was published a decade and a half ago, hospitals have implemented palliative care programs at a rapid pace. From 2000 to 2008, in fact, the number of such programs more than doubled. According to the Center to Advance Palliative Care, 1,299 hospitals, or 31 percent, nationwide had them in 2008 compared with just 632 in 2000. Significantly, of hospitals with more than 50 beds, 47 percent had such a program as of 2008.

Still, says Freer, as long as patients continue to experience needlessly uncomfortable deaths, there remains plenty of room for improvement in end-of-life care—and, by extension, plenty of inroads for palliative medicine.

"I think that a lot of the problems that you saw at the time of the SUPPORT study—inadequate treatment of pain, not communicating patient and family wishes—those things that we would say generally represent a 'bad' dying process—are not a whole lot better, except in pockets," he says.

"I think that's the real benefit of having palliative medicine in academic settings and as an authentic academic area of medicine: There will be better research to see how these systems in medicine can be changed to improve communication and, most importantly, to lessen people's suffering."

## Let Us Define Our Terms, Continued from Page 13

*Albert Goldfain, PhD,* a Blue Highway researcher and recent UB graduate who works in the UB Center of Excellence, notes that the IDO research will be among the first efforts to integrate ontology data across many different scales, an important and difficult issue for biomedical applications.

"While some research has been done on individual genes, for example, and other ontology work has been done on whole organisms, these data have all been developed in separate information silos," he says. "The Infectious Disease Ontology will cross-cut ontologies developed by others at different scales; it will draw and map relationships at the level of individual molecules, cells, organs, organisms and populations, and ultimately provide a way to speed diagnosis and treatment."

In addition to their research on the IDO, researchers from UB and Blue Highway will collaborate on other areas of joint research, including technologies geared for applications in alarm management and data aggregation. Additional areas of potential collaboration include communications protocols for military applications, power management, materials science, battery technology, and biosensors and lab-on-a-chip technologies.

"Blue Highway has a working relationship with UB and is exploring technologies of interest in the area of health care," says Jack Rudnick, senior vice president of legal and government affairs at Blue Highway. "Blue Highway is occupying space in UB's downtown Center of Excellence to facilitate the relevant research and leverage the excellent working opportunities with students, researchers and staff. We look forward to realizing some of the exciting opportunities that collaboration with UB provides."