

ATTENDING

Ruminations on the medical life

IN GOOD COMPANY

A PALLIATIVE CARE EXPERT LISTENS HARD | BY ROBERT MENDELSON



Crunched in the fetal position, an elderly woman arrives at a Cambridge, Massachusetts hospital after months, perhaps years, of neglect. Nobody knows her name. She is silent, except for an occasional groan that most likely stems from the pain of an infected and ulcerated bedsore covering her entire lower back.

The hospital staff admits her immediately. So that she can undergo treatment for the bedsore, dehydration, and other serious ailments, a 23-year-old orderly is charged with lifting this frail, knotted woman out of bed and positioning her in a way that the nurses and physicians can attend to her.

Moving gravely ill, incommunicative people is not something the orderly prepared for in his humanities classes. That's because most honors graduates from the University of Chicago don't aspire to be orderlies. David Barnard was no exception. Upon graduation in 1970, he was awarded a fellowship in history at Brandeis University. But Vietnam changed those plans. It was time for Barnard to fight for his country or fight for his ideals. He declared himself a conscientious objector.

This required him to perform alternative service. He remembers what the draft board told him: "You should not make much money, you should suffer a little bit, and you should do something humanitarian." The board suggested "the hospital route."

His first encounter with the elderly, bedridden woman would be like many others.

Hi, I'm David.

No response.

I need to move you so the nurses can tend to you.

Barnard shifts her position—delicately—cringing inside at the thought of adding to her pain. He gets her settled.

Still no eye contact. He fluffs a pillow, adjusts the blinds. There must be more he can do.

It's bright and sunny today. See? Maybe that will help you feel better.

Nothing.

I'll be back in a bit to see how you're doing.

Barnard's monologue continues for weeks. One day, he tries again to position her comfortably. As he is about to leave, he thinks he hears something—a mumble? He stoops down close to the woman with the blank stare, lowering his ear beside her mouth and hears these words:

"Thank you."

From then on, Barnard went back every day to sit with her, patiently hoping to hear more mumbles. He arranged for other orderlies to do the same.

Eventually, she said more. She was speaking softly and with difficulty, but she was speaking.

Barnard learned her name. (We'll call her Sarah Hale.) He also learned she was good company.

Before long, Hale was telling Barnard stories about her life. She had never married. And she liked to reminisce about her high-flying days as a student at Wellesley College at the beginning of the 20th century.

One time, they were going through their repositioning routine, and just as he was about to move her, Barnard said, *This might sting a bit. Grit your teeth.*

I don't have any teeth, she quipped back.

All right then, grit your gums.

Hale's condition improved to the point where she was ready to be released. Her new friends, Barnard and the other orderlies, hosted a going-away tea party on her behalf. That afternoon, the tears flowed as freely as the tea.

Once his alternative service was completed, Barnard was permitted to resume his

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history studies. Instead, he resigned from the Brandeis fellowship. Health care was the field for him, though he didn't see himself as a clinician:

"I realized, through the experiences I had, that beyond the technology . . . there is something very powerful that can happen at

a human level. I wanted to learn more about that. I felt maybe there was a way I could contribute to training other people in medicine how to function while keeping that dimension in view."

Today, Barnard is a PhD in medical humanities and professor of medicine at the University of Pittsburgh School of Medicine,

where he teaches ethics courses. He also directs the palliative care education program in the University's Center for Bioethics and Health Law. This year, Oxford University Press came out with his new book (he's one of four coauthors), *Crossing Over: Narratives of Palliative Care*.

The *Oxford Textbook of Palliative Medicine* devotes more than 1,300 pages to the subject. Barnard praises that publication, yet he notes, "Life is much more complicated than a textbook." In order to give the medical community a flesh and blood perspective in areas ranging from pain management to spiritual concerns, *Crossing Over* presents patients with terminal illness not as case studies, but as people. Its authors capture the voices of patients, family members, and caregivers in the midst of struggle:

"If I could pull God down from heaven, I'd beat him up."

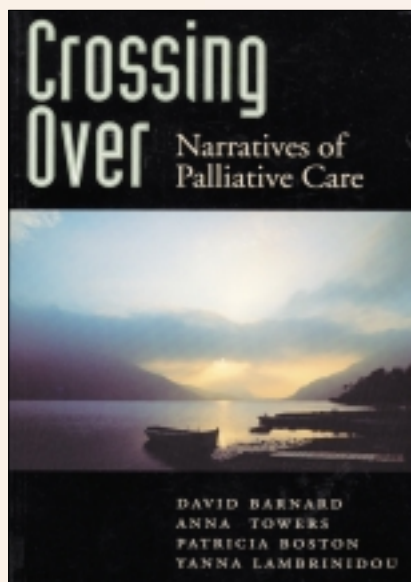
"She's not going to die from an overdose of ice cream."

These are voices Barnard wants heard. They're voices he started listening to nearly three decades ago when Sarah Hale whispered, "Thank you." ■

**Someone offers me lunch —
I say, "First the neck brace off."
I try to spell it with a chart and a straw
between my teeth,
but he mistakes "collar off" for "colour of"
and offers me a spoonful of orange.
It is a very little problem compared
with others'.
They've offered to double my "Prozac."**

—Paula Ferrari

Ferrari—poet, artist, musician, philosopher, and scholar—was diagnosed with amyotrophic lateral sclerosis in 1993 and died three years later. The story of her experience with terminal illness is recorded in *Crossing Over: Narratives of Palliative Care*, from Oxford University Press. Pitt's David Barnard is the lead author.



BOUND UP BY LOVE

LIVES GIVEN, LIVES SAVED

BY EMILY TIPPING

Regan was born on St. Patrick's Day, so she got to wear a green hat. Her mother, Dawn Lynn Check, remembers how quickly nurses replaced the hat with an intravenous line, feeding it into a thread-like vein on her shaved scalp. Regan, now a stubborn yet sociable 19-month-old, fought back when doctors ran a central line to her heart and inserted tubes to bolster her tiny lungs as one deflated, then the other.

That feistiness was a good sign, medical staff told Check, who had given birth to her third child six weeks early. Check remembers how—as they confidently tended to her daughter's physical needs—the doctors and nurses taught her, the parent, how to love her seemingly fragile new child. Don't just brush a hand over her, they urged. Don't caress her lightly. Lay a firm hand on her. Be strong for her.

Check says Regan absorbed that strength. The toddler with blonde pigtailed loves to be hugged and held but also fearlessly explores her outdoor surroundings in the company of the family dog, George. When no one is watching, the dog-child duo raids the kitchen cabinets for cookies and steals Matchbox cars from Regan's

older brothers to throw down the laundry chute.

Last year, Check, who is a minister and executive director of United Campus Ministry of Pittsburgh, was invited to speak at the School of Medicine-sponsored memorial service that honors those who donated their bodies to advance medical science. Busy caring for Regan, she didn't make it.

This year, on a warm May afternoon in Heinz Chapel, Check takes the pulpit at the Humanity Gifts Registry Memorial Service to tell medical students and family members of donors that, in a sense, Regan is alive because of those noble contributions. Just as she will never forget the compassion and medical skill that saved her daughter's life, Check hopes medical students never forget the lives that enrich their education.

Today, students publicly remember. No dulcet organ accompaniments or sprays of flowers are necessary. L. Mark Lockett, a member of the Class of 2003, shares a eulogy he wrote with his classmates. *They were craftspeople and tradespeople, professionals,*



Regan Check

COURTESY DAWN LYNN CHECK



JOANNE BARTONE/CUDGE

and homemakers; some lived well into their nineties, while others may have died early, untimely deaths. . . . Three other students take turns reading the names of 73 Pennsylvanians who donated their bodies for medical education in the past year. The names are uttered with reverence, careful not to mispronounce. Seventy-three more lives. Seventy-three more stories, some of which may also begin with tales of Matchbox cars, cookie raids, and firm yet tender caresses.

Each name is read; soon, it's time again to step outside the chapel, where lawnmowers rumble, robins set up house, and tulips etch their brief tall moments scarlet against the sky. It is the kind of day that makes you think of life cycles. The words of a minister echo: "What I hope the medical community will learn is not just how to do a job, but about the gift of real life.

"Life bound up by love." ■