



JANE R. LEBLANC

THESE PAPERS TELL A LOVE STORY

For her memoir, Bloomberg's Amanda Bennett mixes facts (5,000 pages of 'em) with emotion.

Amanda Bennett plants her hands on her face, props her elbows on the table and peers out through splayed fingers. The red nail polish on her left thumb is half missing and looks chewed off. The flesh of her cheeks pushes out through the webbing of her hands and her chin-length, dirty-blond hair falls in her eyes. "I'm trying to think so I can honestly answer the question," she says, suddenly serious. The conversation has turned to her husband's death from cancer and her decision to write a memoir taking on a health care billing system "operated by Satan."

The two-time Pulitzer winner and executive editor of the projects/investigations team at *Bloomberg News* has been re-living her youthful days as a gung-ho reporter for *The Wall Street Journal*, giggling about oddball stories she wrote for the paper's front page – its famed "A-Heds." She tells the story about the bug room at a Toronto museum where beetles gobble up the decaying flesh on animal skeletons to prepare them for exhibit. She talks about the time she climbed a ladder to interview a tightrope walker trying to cross Niagara Falls. "I had to interview him in French at the top of a tightrope. And, this is the part I really like ... I was wearing a dress!" she says, howling at the idea of her showing off her behind to the crowds below.

While she talks, reporters in Bloomberg's Washington, D.C., office wander by the glass-enclosed conference room and sneak a peek, no doubt wondering what's got their ball-busting boss so tickled. She chats

freely about postponing her freshman year at Harvard University and running off to France at 18 without knowing a soul there. ("I think my parents should've had their heads examined.") She paid her own way by starting to work at age 14 – the earliest you could in New Jersey. In Paris, she studied at the Sorbonne, soaked up Baudelaire and smoked Gauloises cigarettes. Back home, with a degree from Harvard, she wanted to "experience stuff" and "go for rides in things" as a reporter. She wrote about the military's first female recruits at Fort Benning, went seal hunting with Eskimos and lived with uranium miners in Alaska. The experiences were "awesome" and "totally cool." She sounds like a teenager circa the '70s.

Beneath the chatty exterior, however, lies an editor with attack instincts, one unafraid to take on the U.S. government or corporate icons. At age 61, Amanda heads up a team of 26 Bloomberg reporters who hunt down stories with what she calls the "moral force" to do good, to help the average person without the Bloomberg power behind them. Her teams have gone after Western companies (HP and McAfee, among others) for providing surveillance systems to authoritarian regimes such as Syria and Tunisia. Her reporters exposed Victoria's Secret for buying African "fair trade" cotton picked by children as young as 12 and 13. During the financial crisis, she led Bloomberg's effort to sue the Federal Reserve to disclose details about the \$2 trillion in emergency loans to cash-strapped banks – a case won in the U.S. Supreme Court. At any one time, she may

have teams working on 12 to 24 projects about difficult, nail-biting subjects ranging from medicine and women's issues to the Chinese government. As an editor, she says, "I'm getting the buzz off 10 stories now instead of just one."

She's won two Pulitzers, awards borne out of the role she sees for herself as a journalist – an avenger of moral wrongs. Her first in 1997, as part of *The Wall Street Journal* team covering the AIDS epidemic, came from her outrage that public health funding was being directed at heterosexuals and teenagers, diverting money from gay adults, the primary group at risk. "They basically delayed addressing who the real victims were for probably another five to eight years," she says. In 2001, she led an investigative team at *The Oregonian* through the underground world of prisoners lost by the Immigration and Naturalization Service. "They'd lose track of them," she says, still incensed. "We found people who'd been there [in jails] for two, three, four years that the system had forgotten about."

Leaning back in her chair, Amanda says marriage and family changed her high-flying correspondent's life. But her husband Terence's death in 2007 gave her yet another battle to wage against a bloated, dehumanizing health care system that failed them, offering seemingly endless tests and scans accompanied by surgeries and risky drug trials, but never giving them the tools to deal with the reality that he was dying. Driven by her doubts and her sorrow, she opened up her life and wrote a memoir, *The Cost of Hope: The Story of a Marriage, a Family, and the Quest for Life*. In the book is a very different Amanda – a not-so-invincible Amanda, a woman learning to live with the loss of a man who enriched her life and infuriated her for 24 years. "He always had his foot in my back. Always," she says. "You're gonna be somebody, Toots ... that was always his thing."

HE LIED TO HER THE FIRST TIME they met. She was a budding correspondent in China's capital Beijing, working for *The Wall Street Journal* in 1983. Frustrated with a story that wouldn't come together, she ventured out to a fellow journalist's late-night party. Through the throngs of people, she spotted an odd, bow-tied man wearing a three-piece suit and horn-rimmed glasses. Mr. Bow Tie beckoned her over, and she discovered he was the missing piece to her stumbling story – a Fulbright scholar studying Sino-Soviet relations. After leaving at close to 3 a.m., Amanda realized she

had no idea what the man's name was or how to find him for follow-up. Unable to use their conversation for her story without a name, she forgot all about it, until she ran into him a few months later at a bank opening.

They immediately exchanged cards. His read: *Terence B. Foley, Country Director, American Soybean Association*.

Amanda's temper began to boil. "Soybeans? You said you were a Fulbright scholar. Studying Sino-Soviet relations?"

"You're cute. You're a journalist. I wanted to talk to you. Journalists are always working. How long would you have talked to me if I told you I was in soybeans?"

Amanda was flabbergasted. "You a—hole! You could have gotten me fired!"

She stomped away.

Naturally, she married Mr. Bow Tie.

In the years that followed, they had two children, Terry in 1988 and Georgia in 1998 (adopted at age 4 from China). They bounced from one end of the United States to another for Amanda's career – from Georgia to Oregon to Kentucky and then Pennsylvania. Each time, she moved up in management, from the *Journal's* Atlanta bureau chief, to managing editor/projects of *The Oregonian* in Portland, to editor of the *Lexington Herald-Leader* in Kentucky and finally, to Pennsylvania as the top editor at *The Philadelphia Inquirer*.

Yet Amanda was often the one hesitant about the moves. When the *Journal* first offered her the bureau chief's position in Atlanta (a chance to be "not just bossy but a boss," she says), the idea of uprooting her young family scared her. Not Terence. His idea of fun was moving every year, meeting new people and learning new things. He was packed and ready to go before she was. Wherever they landed, he reinvented himself—working at *The Wall Street Journal* as a radio journalist (Amanda found out when she ran into him in the *Journal* cafeteria), creating context for CNN online while in Atlanta, and becoming director of a new Asia Center at the University of Kentucky. A Chinese historian, he got his Ph.D. at 61, more than 40 years after starting his studies.

Amanda was pushing her team at *The Oregonian* to finish what would become a Pulitzer Prize-winning piece on the INS when Terence fell ill. "There are huge chunks of our life I remember nothing about," she says. "But this ... God, I remember this one really clearly." At work, she was in prosecutorial editor mode. What had begun as a local tale about a Chinese

girl held for eight months in a county jail with hardened criminals because of INS bumbling had grown into a series with a national scope. The paper's Pulitzer Prize for Public Service in 2001 would seal Amanda's public persona as a hard-hitting journalist willing to take on wrongdoing with the "moral force" of an avenger. But at home, her life was about to come unglued.

THEIR SON TERRY WAS CELEBRATING his twelfth birthday and the house was full of kids on a sleepover. "I remember the pillow fights downstairs. I remember what I said to little Terry's friend Preston on the stairs. I can remember how messy the house was." The morning after the sleepover, with kids still waiting to be picked up, Amanda found Terence doubled over in bed, his stomach wracked with pain. "I remember thinking I *had* to get him to the hospital quickly or to the doctor quickly, and the kids were still here, and their parents were coming to pick them up, and I couldn't leave them." Only after the last child was gone did the family rush to the emergency room, Terence gritting his teeth to hide the pain. At the hospital, with the children parked in a waiting area with toys, Terence finally broke down and curled into the fetal position, screaming.

A scan revealed a problem with his intestines. The diagnosis was severe ulcerative colitis. Almost as an aside, the doctor mentioned a "shadow" on Terence's kidney. "You are going to want to get that looked at," he said casually. Amanda remembers being annoyed with the doctor. *Don't talk to me about a shadow. C'mon, focus on what we're talking about here! This guy hurts!* "I remember how peculiar it was in retrospect that we really didn't pay attention to what he was talking about," she says. Weeks later, they found out the shadow on his kidney was cancer. For seven years, Terence underwent one treatment after another – Interleukin-2, Avastin, Nexavar, Sutent. Twice he was on the verge of death, but rallied back to health. In 2007, at age 67, he died. The cancer had spread to his lungs and brain.

Like any widow, Amanda struggled to deal with her feelings. Terence's medical bills came to \$616,816, much of it paid by Amanda's insurance. The real issue for her wasn't the cost, but a system "so maddeningly complex to navigate," she says, that it took days, weeks, months, even whole years of their lives to figure it out. A system, she adds, that left her "not entirely sure we did the right thing" –

even years after Terence's death. The medications Terence tried were all part of trials. Medical papers kept referring to them by their technical names. Even knowing which trials to enter was complex. Amanda would call drug companies, pleading with them for direction. "I know you can't say if it'll work," she'd say, "but which is worth pursuing?" Was it worth driving 1,000 miles both ways for one drug? Was it worth flying somewhere each month for another? There were no answers. She scoured the Internet, joining message boards full of strangers dissecting their personal stories to figure out which drugs to try, which to avoid, which hospitals were best, which trials were most promising.

After seven years of wandering lost in a maze of health care choices, with no real direction or help, she'd had enough, especially near the end of Terence's life. The avenging crusader, who took on evil for others at work, vowed to take on the system for her own family. She wanted answers.

Had they sought the right treatments? Were the experimental drug trials worth it? Should they have spent more time together? Given up earlier?

IT TOOK HER A YEAR AFTER TERENCE'S DEATH to realize she was in a unique position to write about her experience. Sarah Palin and the death panels were all over the news. "It's just sort of what writers do, journalists do," she says. "You try to turn your experiences into something that makes sense." But not every journalist has the guts to take on the system or the connections to put the story on the cover of *Bloomberg Businessweek* magazine and help others trapped in the system. "I realized our story could help other people in a way that perhaps they could not help themselves," she says. "I could do something nobody else could do. I could take my own private experience—which is an experience that everyone, everyone, will have sooner or later—and get a 3D look that almost nobody sees." It's that outrage, that "moral force," she always looks for in her stories.

To write *The Cost of Hope*, she went through 5,000 pages of documents accumulated from six different hospitals. She interviewed four insurers and Medicare as well as her husband's three oncologists and a surgeon. She dredged up memories of her husband's cancer diagnosis, the drug trials that didn't work, the side effects from the drugs, the sleepless nights, the pain. With the help of her researcher, Chuck Babcock, she built a timeline for medical procedures,



then began adding her family life around that. She went back to the scene – to Oregon, where it all started. She sat in front of their old house so she could re-create the drive she and Terence took over and over again to Providence Portland Medical Center. She even tracked down a pathologist she'd never met, the man who diagnosed her husband's disease as collective duct cancer of the kidney – Dr. P. Holbrook Howard. She wanted to see slides of her dead husband's cancer cells under a microscope.

When she arrived at the doctor's office, Terence's slides were already on his desk – 19 of them, labeled "Terence Foley/Case #P01-922." She and the doctor carried the slides into a conference room filled with large filing cabinets reminiscent of old libraries. In each cabinet were slides of misbehaving cells – a sort of Dewey decimal system of disease. The slides were fixed with formaldehyde, preserving the cells and the disease that had caused Terence so much pain.

Amanda and the doctor lowered their heads to a microscope with dual heads and, together, viewed the remnants of Terence. "I was excited," she says. "This is cool! I had to stop and say to myself, I suppose I should feel grossed out about this. But I didn't. Terry would think this was really cool. He would've been torn because he really hated gross stuff, way more than I did. But he also *really* liked knowing stuff. He would have just taken his note cards out and asked the guy a million questions and covered both sides of

the index cards. So that's what I was thinking. It wasn't grim. It wasn't a downer."

She had to fight against her reporter's instincts to be dispassionate and instead force herself to write about her everyday life and her feelings. "I thought that people would be most interested in all the facts I uncovered," she admits. "Who's gonna be interested in my stories? It's just my life. Who cares about that?" It turned out that those stories—of Terence smuggling video tapes from the U.S. into Beijing, of Amanda skydiving as he looked on from a nearby plane, of their humorous fights about Christmas trees—were "what people were most interested in," she says. Her editor kept saying to her, *Stay on story. Stay on story.*

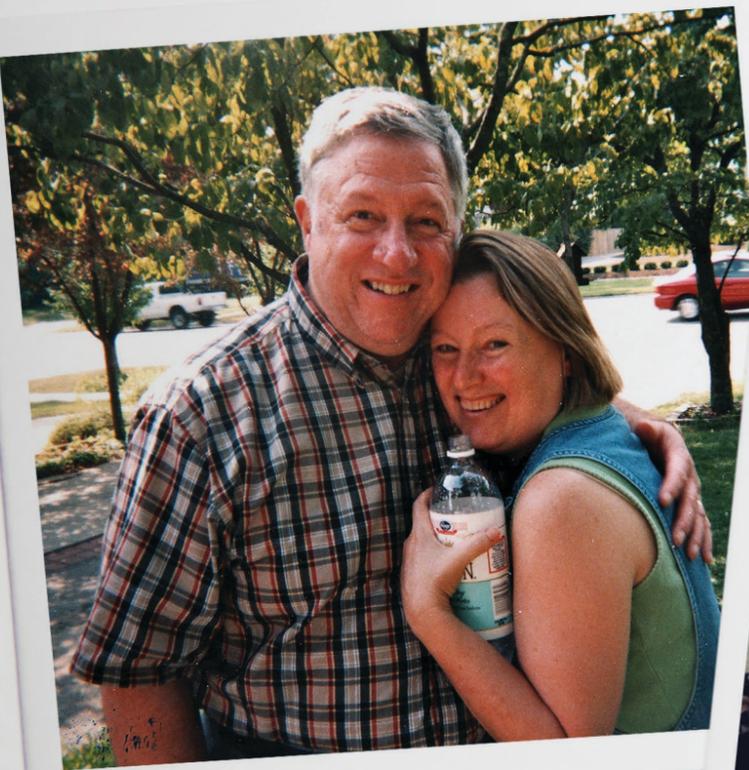
The most powerful scenes in the book come from Amanda re-living the worst moments. In 2002, when his cancer first returned in his lungs, he hid his diagnosis from Amanda and his children. A doctor placed him on a medical trial with such severe side effects that one day their son, Terry, found him in bed, on fire with fever but shaking from chills under a pile of blankets. Amanda, rushing home from work, got only half-hearted explanations, but she kept pressing.

"I had a cold ..., he says, "so I ..."

She panicked. "Terence, this is bullshit. Tell me. NOW."

He finally relented. "The cancer is in my lungs. I have six to nine months left."

She felt, she writes, "the electricity of fear." As she lay next to her husband in bed, the fear



TWO DECADES OF LOVE ... THEN LOSS
(LEFT TO RIGHT) Scenes from a marriage: Terence and Amanda, with the kids Georgia and Terry — long before cancer dropped them into the lap of a “Satan-designed system.”

Photos courtesy Bennett family

she had been holding back burst through her defenses. She could barely breathe or think. That night, sitting alone in her living room, with Terence asleep upstairs, she realized for the first time what she would lose if her husband died. “I realize more clearly than ever before how much over the years I have come to see myself through his eyes,” she says in her book. “The moves I would not have made. The chances I would not have taken.” That night, she resolved not to let him die.

Two days later, she went with Terence to see his secret doctor, Dr. Scott Pierce. Amanda shoved an armful of printouts, names of doctors, hospitals, drugs and descriptions of clinical trials at Pierce.

“This is who you were protecting?” the doctor asked Terence, incredulous.

Sheepish, Terence shrugged. “Guy’s a head case,” Amanda says.

The doctor looked at Terence, who shrugged again. “She may save your life,” Pierce said.

Amanda went into research hyperdrive, researching Interleukin-2 (IL-2), the drug Terence had been taking secretly. She happened upon a Cytokine Research Group, looked up papers in obscure journals and tried to make sense of titles such as “Clinical efficacy of adoptive immunotherapy by IL-4 activated tumor-infiltrating lymphocytes in patients with advanced cancer.” *What does that even mean?*

she wondered. Some papers used weird abbreviations like CR, OR, PR and DR. Even more aggravating, she discovered that most research centered on the most common form of kidney cancer, not what Terence had. She found one paper from 1993 that suggested evidence, but not proof, that IL-2 provided a longer survival. “How long? *HOW LONG?*” Almost at the end of her rope, she shouted out loud at the papers. She was frustrated and confused, but Amanda Bennett never backs away from a challenge.

WHEN SHE TALKS — AND SHE TALKS

constantly these days at universities, health care conferences and the trendy TEDMED conferences on health and medicine — she talks about the end of their 7-year-long journey to save Terence. About the confounding medical trials with unknown risks and rewards, the painful side effects from drugs offering no help, and the frustrating dead-end phone calls to doctors and nurses. She starts her story sometime after midnight on December 8, 2007,

the night that Dr. Eric Goren told her that her husband might not live until morning. She tells the story of how confused she was that night. She talks about how she met Terence, how he tricked her into talking to him, how many of their friends (even Amanda, for a while) thought he might be a spy, how he played 15 musical instruments, spoke six languages, loved poetry. She talks about the man she loved for more than 20 years. And then, this once-very-private journalist, talks about herself. “The thing I learned about myself is that denial isn’t even close to a strong enough word to describe what we go through at the end of a loved one’s life,” she says.

“One of the things I found, particularly towards the end of his life, there was a doctor for everything. There was a doctor for his throat, a doctor for his kidney, a doctor for his colon, another for the cancer, another for skin, and one, the hospitalist, for the hospital care,” she tells her audiences. “But there was nobody who was just interested in him. Nobody looking at

Terence Bryan Foley. I was the only one looking out for him.”

During the last days of Terence’s life, they saw 27 people in four days, including nine doctors. Amanda could never find out who was in charge. She had to make the final decision to remove Terence from life support. Even when she interviewed his doctors for her book, they were still arguing over what exactly he had. On the talk circuit, she is the avenger calling attention to the system’s failures — “the overtreatment going on in this Satan-designed system.” “It’s a system that didn’t serve me, didn’t serve Terence well, and I don’t think is serving the hospitals and doctors and drug companies as well as it should either,” she says.

Amanda used to fantasize about reading a poem to Terence at the end about Roman politician Mark Antony, who fought his entire life and won at everything, until he didn’t. He finally realizes he has lost the city of Alexandria, and it’s time to let go. The poet tells him how to have a hero’s goodbye. Amanda never got the chance for a hero’s goodbye. She and Terence never slowed down long enough. They never slowed down because she never truly believed he would die. “When I went back and looked at our journey,” she says, “people mentioned

hospice to us repeatedly. But I wouldn’t listen. ‘Hospice was for people who are dying,’ I said, ‘and that’s not Terence.’”

The question most frequently asked about her book is: “Wasn’t it awfully tough to write?” She always gives the same answer: “It wasn’t hard at all. In fact, it was wonderful.” The personal memories were easy for Amanda to write. Even fun. She would lie on her sofa, typing out their story on her computer. “It’s like I got another year with him,” she says. “I got to play with him for another whole year.” Her book wasn’t just a chance to spend more time with Terence but to right a wrong — to save others from the baffling, confusing journey that she and Terence endured for seven years.

These days, her children are grown and she’s remarried to Don Graham, CEO of *The Washington Post*. But every day, without fail, she takes time to talk to Terence. Mostly she talks to Terence about the kids, how they’re doing, day-to-day life. (Not out loud. “I’m not that whacked,” she says. It does freak out her kids, though.)

She did some major bargaining with him about her book. “I kind of negotiated with him about what I could write about and what I couldn’t write about. He was a very private

guy, so I was talking to him, you know, *Look, how about if I say this? OK, how about this piece? I know you don’t think of this in the same way I do, but this is my book, dammit, not yours.*” She is glad that they know who Terence was.

In the first year after his death, she often wondered if she and Terence had gone about things the right way. And now, after committing her private life to the page, after detailing their fights, their laughs, their pain and their love for all the world to see, Amanda Bennett has her answer.

“As sad as I am at our silent farewell, I wouldn’t trade away any of those years of fighting for life. Would I do it all again? Absolutely. I couldn’t not do it again,” she says.

Terence used to tell a story about his Uncle Bob that proved apocryphal. Climbing aboard a landing craft before the invasion of Normandy, Bob’s sergeant was said to have told his men that by the end of the day, nine out of 10 of them would be dead. Bob said each one looked around and felt so sorry for those other nine sons of bitches.

“We believed beyond logic that we were going to escape the fate of those other nine sons of bitches,” Amanda says, “and it’s hard to put a price on that kind of hope.”