



End-of-Life Warning at \$618,616 Makes Me Wonder Was It Worth It

By Amanda Bennett - Mar 04, 2010

March 4 (Bloomberg) -- It was some time after midnight on Dec. 8, 2007, when Dr. Eric Goren told me my husband might not live till morning.

The kidney cancer that had metastasized almost six years earlier was growing in his lungs. He was in intensive care at the Hospital of the University of Pennsylvania in Philadelphia, and had begun to spit blood.

Terence Bryan Foley, 67 years old, my husband of 20 years, father of our two teenagers, a Chinese historian who earned his Ph.D. in his 60s, a man who played more than 15 musical instruments and spoke six languages, a San Francisco cable car conductor and sports photographer, an expert on dairy cattle and swine nutrition, film noir and Dixieland jazz, was confused. He knew his name, but not the year. He wanted a Coke.

Should Terence begin to hemorrhage, the doctor asked, what should he do?

This was our third end-of-life warning in seven years. We fought off the others. Perhaps we could dodge this one too. Dr. Keith Flaherty, Terence's oncologist, and I both believed that a new medicine he had just begun to take would buy him more time.

Keep him alive if you can, I said. Let's see what the drug, [Pfizer Inc.](#)'s Sutent, can do.

Terence died six days later, on Friday, Dec. 14, 2007.

What I couldn't know then was that the thinking behind my request -- along with hundreds of decisions we made over seven years -- was a window on the impossible calculus at the core of the U.S. health-care debate.

Expensive Last Chances

Terence and I didn't have to think about money, allocation of medical resources, the struggles of more than 46 million uninsured Americans, or the impact on corporate bottom lines. Backed by medical insurance provided by my employers, we were able to fight his cancer with a series of expensive last

chances like the one I asked for that night.

How expensive? The bills totaled \$618,616, almost two-thirds of it for the final 24 months, much of it for treatments that no one can say for sure helped extend his life.

In just the last four days of trying to keep him alive -- two in intensive care, two in a cancer ward -- our insurance was charged \$43,711 for doctors, medicines, monitors, X-rays and scans. Two years later, the only thing I know for certain that money bought was confirmation that he was dying.

Some of the drugs probably did Terence no good at all. At least one helped fewer than 10 percent of all those who took it. Pharmaceutical companies and insurers will have to sort out the economics of treatments that end up working for only a small subset. Should everyone have the right to try them? Terence and I answered yes. Each drug potentially added life. Yet that too led me to a question I can't answer. When is it time to quit?

Science, Emotion, Costs

Congress didn't touch the issue in last year's attempt to pass a [health-care bill](#). The mere hint of somehow limiting the ability to choose care as aggressively as Terence and I did created a whirlwind of accusations that the ill, aged and infirm would be forced before government "death panels."

As the debate heated up, I remembered the fat sheaf of insurance statements that arrived after Terence's death. Our children, Terry, 21, and Georgia, 15, assented to my idea of gathering every record to examine what they would show about end-of-life care, its science, emotions and costs. I knew Terence would have approved.

Along with my colleague Charles Babcock, I spent months poring over some 4,750 pages of documents collected from six hospitals, four insurers, Medicare, three oncologists, and a surgeon. Those papers tell the story of a system filled with people doing their best. And they raise complex questions about a health-care system that consumes 17 percent of the economy.

Days to Decipher

As I leafed through the stack of documents, it was easy to see why 31 percent of the money spent on health care goes to paperwork and administration, according to research published in 2003 by the New England Journal of Medicine. That number has either stayed the same or grown, said Dr. [Steffie Woolhandler](#), a professor at Harvard Medical School and a co-author of the study cited by the journal. Some bills took days to decipher. What did "opd patins t" or "bal xfr ded" mean? How could I tell if the dose charged was the same as the dose prescribed?

The documents revealed an economic system in which the sellers don't set and the buyers don't know

the prices. The University of Pennsylvania hospital charged more than 12 times what Medicare at the time reimbursed for a chest scan. One insurer paid a hospital for 80 percent of the \$3,232 price of a scan, while another covered 24 percent. Insurance companies negotiated their own rates, and neither my employers nor I paid the difference between the sticker and discounted prices.

‘It’s Completely Insane’

In this economic system, prices of goods and services bear little relation to the demand for them or their cost to make -- or, as it turns out, the good or harm they do.

“No other nation would allow a health system to be run the way we do it. It’s completely insane,” said [Uwe E. Reinhardt](#), a political economy professor at Princeton University, who has advised Congress, the Veteran’s Administration and other agencies on health-care economics.

Taking it all into account, the data showed we had made a bargain that hardly any economist looking solely at the numbers would say made sense. Why did we do it?

I was one big reason.

Not me alone, of course. The medical system has a strong bias toward action. My husband, too, was unusual, Flaherty said, in his passionate willingness to endure discomfort for a chance to see his daughter grow from a child to a young woman, and his son graduate from high school.

Pricing Hope

After Terence died, Flaherty drew me a picture of a bell curve, showing the range of survival times for kidney cancer sufferers. Terence was way off in the tail on the right-hand side, an indication he had indeed beaten the odds. An explosion of research had made it possible to extend lives for years -- enough to keep our quest from having been total madness.

Terence used to tell a story, almost certainly apocryphal, about his Uncle Bob. Climbing aboard a landing craft before the invasion of Normandy, so the story went, Bob’s sergeant told the men that by the end of the day, nine out of 10 would be dead. Said Bob, on hearing that news: “Each one of us looked around and felt so sorry for those other nine poor sonsabitches.”

For me, it was about pushing the bell curve. Knowing that if there was something to be done, we couldn’t not do it. Believing beyond logic that we were going to escape the fate of those other poor sonsabitches.

It is very hard to put a price on that kind of hope.

The Kidney Shadow

We found the cancer by accident, on Sunday, Nov. 5, 2000, in Portland, Oregon.

Our son Terry had had a dozen friends over for his 12th birthday. I was making pancakes and shipping the boys home. Terence had been having stomach cramps for weeks. Suddenly he was lying on the bed, doubled over in pain. Our family doctor ordered him to the emergency room.

We were immediately triaged through. Not a good sign, I thought. The kids sat on the waiting room floor spreading Barbies and X-Men around them, while Terence writhed in a curtained alcove.

When he returned from a scan, the doctor said, almost as an aside: There's a shadow on his kidney. When he's feeling better, you'd probably better take a look at it. We were both annoyed. Why would we even think about a shadow on his kidney? His kidney wasn't the problem. He was in such pain he could barely breathe.

'We Got It'

The cause turned out to be a violent ulcerative colitis. The damaged colon was removed on Dec. 13. The surgery left him so weak that he spent three weeks, including Christmas morning, immobile in a chair. Colleagues packed meals. My sister wrapped presents. My boss sent her husband to put up our lights. In pity, I got Terence the cat he had long wanted, an orange kitten howling in a box under the tree.

And the shadow? We were so grateful he was out of pain that we would have ignored it had someone at the hospital not called to urge us to address it. Within a month, Terence was in surgery, and Dr. Craig Turner had taken out the diseased kidney.

Emerging from the five-hour operation on Jan. 18, Turner confirmed the worst: He thought the shadow was cancer. A week later, when Terence was well enough to walk into the doctor's office, Turner was reassuring.

"We got it all," he said. Terence was visibly moved.

"Thank you for saving my life," he said.

'We Were Lucky'

Kidney cancer is uncommon, accounting for less than 4 percent of all cancers, or about 50,000 new cases in the U.S. last year, according to the [Kidney Cancer Association](#). Terence was typical: an older man, overweight and an ex-smoker. The disease is symptomless for a long time, so most kidney cancers are discovered accidentally, or too late. We were lucky.

The first tool for fighting it is usually the one used since medieval times: the knife, or its technological equivalent. If a tumor is removed early enough, before it flings microscopic cells into the bloodstream that can implant in other organs, surgery is close to a cure.

The statistics looked good. By the traditional method of staging -- a 7 centimeter tumor with no sign of having spread -- Terence had an 85 percent chance of surviving five years.

The bills from [Regence Blue Cross & Blue Shield of Oregon](#) show the operation was relatively inexpensive, too, just over \$25,000, or only about 4 percent of the total charged to keep Terence alive. Insurance paid a discounted \$14,084. Terence and I paid \$209.87.

The lab soon cast a chill on our optimism.

Only 50 Cases

Terence had collecting duct cancer, the rarest and most aggressive form, named for the part of the kidney where it is thought to originate, according to the pathology report. If that was correct, Terence had almost no chance of making it to the end of the year. In every study I could find, almost everyone with collecting duct cancer died in months, sometimes weeks.

Unlike others, most kidney cancers don't respond well to chemotherapy. There was no accepted treatment after surgery. What's more, there was almost nothing known about collecting duct cancer. In all the medical literature at that time, Turner and I could find only 50 cases documented worldwide, and nothing had proved effective in halting it.

"Watchful waiting" was the recommended path.

Waiting for him to die was what we feared.

He didn't die. He got better. We didn't know why. We tried not to think about it.

'Too Much Stuff'

By the spring of 2002, we had moved to Lexington, Kentucky, where I was the editor of the newspaper and Terence was creating an Asia Center at the University of Kentucky. He began moving Chinese and Japanese history books to his office. On Saturdays we drove through the bluegrass to take seven-year-old Georgia to riding lessons. We reluctantly let 13-year-old Terry crowd-surf at his first rock concert.

Then, on May 6, 2002, I was at work when Terry called, panic in his voice. "Mom, come home. Dad is very sick."

His father was in bed, his face flaming with fever, shaking with chills under a pile of blankets.

He could barely speak.

“The cancer is in my lungs,” he said. “I’ve got six to nine months left.”

A scan had spotted the cancer’s spread. Not wanting to worry us, Terence had secretly begun taking Interleukin-2. If he recovered, he figured, we would never know how close he came; if he died, he would have spared us months of anguish.

Suddenly his actions over the last several weeks made sense. He had been giving away musical instruments and pieces of art. “I have too much stuff,” he had told me, a bizarrely improbable statement coming from him.

Bow Ties

What he didn’t reckon on was that the drug would make him violently ill. But it was the only possible therapy at that time. Injections of the protein -- at \$735 a dose -- were intended to stimulate the immune response to help fight off the cancer’s invasion.

The overall response rate was about 10 percent. For most, it did nothing.

That evening, for the one and only time, I felt pure terror. I spent the night awake in our dark living room. A few days later I visited a therapist.

“I can’t survive without him,” I said.

“What does he say when you feel this way?” she asked.

“He says I can handle anything.”

“You’ll need to say that to yourself.”

On a rainy Monday last September, I visited Terence’s oncologist in Lexington. Dr. Scott Pierce remembered his patient, his grey fedora and bow ties, and his personality.

The Long Odds

“The first thing he said was, ‘Doc, do you have any female patients who have recently died? I need to find a widower so my wife can meet her next husband,’” Pierce recalled. Terence had learned he was going to die, and the first thing he thought was to look after me.

Knowing the long odds, Pierce told me he had prescribed Interleukin-2 simply because it was all there was.

Terence stopped taking it after just a few weeks, unable to stand the side effects.

I shook off my fear and plunged into the Internet. If there was something out there that could save him, I was going to find it. One colleague had been snatched from dying of AIDS by a chance introduction to a doctor who prescribed an experimental antiviral cocktail. Another had beaten leukemia with a cutting-edge bone marrow transplant. We could defeat this, too.

I downloaded papers, presentations to the Kidney Cancer Association, abstracts from the [National Library of Medicine](#). I called researchers and oncologists, pathologists and fellow journalists. When the research became overwhelming, I hired a retired nurse to help. My boss's wife, a nurse herself, began her own information quest. I became part of an online community. After I messaged one couple about a clinical trial in Texas, they offered us their spare bedroom.

Terence's Dream

Earlier this year, I called "LMODRNGRRL," a frequent cancer-forum poster from those years. A furniture dealer named Laura Lear, she told me she had left her business in Los Angeles to help her boyfriend in New York. Robert Cowan, also a furniture dealer, had collecting duct cancer. Like me, it was she who drove the search for information. "I spent all my time online," she said. She firmly believes the drug they settled on -- [Novartis AG](#)'s Gleevec, for which insurance paid \$3,000 a month -- extended his life, although it was never approved for use on kidney cancer. He died in September 2003 at 43, almost two years after his diagnosis.

Throughout the spring and summer of 2002, Georgia, then 8, rode her bicycle up and down the shaded streets of South Ashland Avenue. Thirteen-year-old Terry and his friends Shannon, Hughes and Tanner came in last at their first battle of the bands. Terence sounded optimistic.

"It's my dream," he said. "Some day we're going to gig together."

Visiting Pompeii

The truth was we were both shaken at the dire prognosis.

"What would you regret dying without having seen?" I asked. He answered without hesitation: "Pompeii."

So we pulled Terry from his 8th grade class, Georgia out of 2nd, and flew off to Italy to see the excavated remains of the city once buried under volcanic ash. We walked the cobbled streets, poked into frescoed houses, taverns and baths, and took an eerie comfort from the 2,000-year-old shapes of families huddled together, trying to ward off disaster.

By then our research had led us to the Cleveland Clinic, where Dr. Ronald Bukowski has specialized in kidney cancer for more than 20 years. At our first meeting, in August 2002, Terence explained that he had the rare collecting duct cancer.

A Clinical Trial

“No you don’t,” Bukowski said.

We were confused. How did he know?

“You’re sitting here,” he said. “If you had collecting duct, you would be dead.”

Bukowski argued that the disease was growing so slowly that we should simply watch and wait. We did, until December 2005, when a scan showed the cancer in his lungs had begun to grow.

By this time, drugs designed to attack a tumor’s blood supply were appearing to slow the growth of a wide range of cancers. Bukowski recommended we enter a clinical trial, which at that time was pretty much the only way to get these targeted therapies. He referred us to Flaherty in Philadelphia, where we had moved in June 2003 when I changed jobs.

The drugs Flaherty was testing -- Avastin and Nexavar --had showed promise individually. The trial would find out how they worked together.

Terence signed papers agreeing to more or less standard terms: The manufacturers, [Genentech Inc.](#) and [Bayer AG](#), would pay for the drugs; we, or our insurers, would cover all other costs.

Cancer in Retreat

In March 2006, he took his first intravenous dose of Avastin, an hour-long process, and swallowed his first Nexavar.

The side effects were hard. There were rashes, sometimes debilitating stomach pains. But he continued teaching, picking up the kids at school, studying and writing. He worked on his book of Chinese poetry. He decided to learn to play the violin and to read and write Arabic. Every two weeks he went for an Avastin drip, and every month for a chest scan. Every month we waited for the results.

At first the cancer didn’t budge. Then it began to retreat.

I learned that over the years of Terence’s battle with cancer, some insurers drove harder bargains than others. In December 2006, for example, UnitedHealthcare, a unit of [UnitedHealth Group Inc.](#), paid \$2,586 to the University of Pennsylvania hospital for a chest scan; in March 2007, after I switched employers, [WellPoint Inc.](#)’s Empire Blue Cross & Blue Shield paid \$776 for the same \$3,232 bill.

'Any Soldier'

The entire medical bill for seven years, in fact, was steeply discounted. The \$618,616 became \$254,176 when the insurers paid their share and imposed their discounts. Of that, Terence and I were responsible for \$9,468 -- less than 4 percent.

During the trial, Terence packed boxes for the troops in battle, loading them in our kitchen with deodorant, Wet Wipes, Mars Bars, Kool-Aid, beef jerky, batteries and magazines. A veteran of Naval intelligence and the Air Force reserves, he walked almost every day to the post office with a box addressed to "Any Soldier." Behind the counter, the smiling lady with the long red hair extensions became his friend.

Every so often a soldier in Iraq or Afghanistan would drop him a thank-you note.

Life went on.

Then, in August 2007, from half a world away, I heard the cancer return.

I was working in China when he coughed during one of our phone calls. By the time I got home he knew it was because of the growth of one of the lung's cancerous spots.

\$27,360 a Dose

By now, more than six years since we first saw the shadow, I was used to the scares. Avastin's side effects -- fatigue, stomach ailments, rashes -- had been getting him down, and the doctor had agreed back in May to let him stop treatments. So we'll go back on the Avastin, I thought, or cut out or laser out the growth, add new treatments and go on.

At a retirement party a few days later, my heart ached for my dear friend, whose breast cancer had returned. What were our lives going to be like without her? How were we going to comfort her husband and daughter?

Terence coughed through the dinner.

The bills and records document our renewed fight as summer in Philadelphia turned to autumn. Terence resumed Avastin. Because he wasn't in a clinical trial, our insurance company was billed: \$27,360 a dose, for four treatments, more than the cost of the surgery to remove his kidney in 2000.

An Unacknowledged Battle

He coughed almost continuously. His weight plunged. He needed help on the stairs. He began to use a cane. When his friend Woody came to visit, he couldn't muster the breath to blow his cornet. He

coughed and coughed and coughed.

In the last week of October, he called me at work.

“I can’t pick Georgia up at school,” he said. “I can’t get out of the chair.” On Halloween, his Dracula costume stayed in the basement. We put the candy on the doorstep.

On Nov. 8, we saw a specialist, Dr. Ali Musani. Unable to stand or sit unassisted, Terence lay on the floor and refused to get up. Alarmed, Musani admitted him to the hospital.

He was there for four days, during a quiet, unacknowledged battle. On one side were Flaherty and I, believing this to be a temporary setback. On the other were doctors and nurses preparing their patient for the end.

On Nov. 10, before discharging him, a doctor propped one of Terence’s scans on a light board and showed us a blizzard of white spots, thousands of tumors covering his lungs.

Avastin wasn’t stopping it.

Terence Was Game

Flaherty and I weren’t going to give up. Sutent, another targeted therapy, had been approved the year before. It worked as Avastin did, by stopping cancer’s ability to build extra blood vessels to feed its growth, but in a different way. One \$200 pill a day. A shot at more life.

Sutent might have even more serious side effects -- rashes, fatigue, stomach distress, strokes -- but Terence was game. He began taking it on Nov. 15.

At home, he drew a line down the middle of a piece of paper. On one side he wrote things to throw away. On the other, things to keep.

“Stop that!” I snapped. “You aren’t going to die.”

I prepared for what I expected would be a new phase of our life. I found protein drinks online and protein bars in a bodybuilding shop. I got forms for a handicapped license plate, and looked into outfitting our row house with a stair lift.

210 Calories

He was no longer able to get in and out of bed alone, so I hired a health aide. Whatever he craved, I bought. I wrote down everything he ate. Cold grapefruit slices. Chicken noodle soup. Clam chowder. I counted the calories he consumed one day: 210.

On Friday, Dec. 7, just as the aide was packing to leave, Terence looked up, startled, as the corners of his mouth foamed bright red with blood. It was a struggle to get him down our narrow stairs to the ambulance.

In the emergency room it was clear something was seriously wrong. "What's your name?" asked the ER doctor. Terence responded correctly. "What's the date?" Terence gave the doctor what the kids and I recognized as "Daddy's 'Just how dumb are you?' look." But he couldn't answer.

"Who's the president of the United States?" That triggered something. "That moron Bush," he said.

Terence was admitted that night to a ward where Eric Goren was doing his last intensive care overnight shift of a three-year residency. In a small break room, alongside vending machines selling soft drinks and chips, Goren told me that bleeding from the lungs might suddenly become uncontrollable. If that happened, what should he and his team do?

No Heroic Measures

I wanted to see whether Flaherty still thought Sutent could make a difference. I couldn't reach him. Goren and I settled on what the hospital called Code-A. Do everything possible to prevent a major bleed or anything life-threatening. Don't take heroic measures if death seems inevitable.

I called the children in. My sister picked up Georgia at a sleepover, and Terry's friends Suzie, Ben and Will brought him from a party.

My decision, so hard on Saturday, was easy by Monday. The scans now were showing signs of cancer in his brain, surrounded by a cascade of hundreds of tiny strokes. I had Terence's signed living will, but I didn't need it. I knew what this man who lived for books, music and ideas would want.

Flaherty arrived. He looked shaken.

"I didn't expect this," he said.

Reading Their Goodbyes

That afternoon I signed the papers transferring Terence to hospice. The next day, Tuesday, the hospital staff took away the machines and the monitors. The oncologists and radiologists and lab technicians disappeared. Another group of people -- hospice nurses, social workers, chaplains and counselors for me and the children -- began to arrive one by one, as the focus shifted from treating Terence to easing our transition.

For the next three days, with Terence in the same hospital bed, we spent \$14,022 on the medications

Ativan and Dilaudid, and on monitoring for him and counseling for a different kind of pain management for the children and me. The cost was less than a third of the previous four days' \$43,711.

Terence drifted into a coma on Tuesday. I e-mailed his friends and read their goodbyes aloud, hoping he could hear and understand. I slept in a chair. At about 2:30 a.m. Friday, a noise in the hall startled me. I awoke just in time to hold his hand as he died.

They gave me back his wedding ring the next day.

Looking back, memories of my zeal to treat are tinged with sadness. Since I didn't believe my husband was going to die, I never let us have the chance to say goodbye.

Black-Bordered Notes

Ten days later, the kids hung Daddy's Christmas stocking alongside our three. I mailed the cards he had addressed months earlier, slipping in a black-bordered note. I threw away the protein bars, gave the energy drinks to a shelter and flushed an opened bottle of Sutent down the drain.

Would I do it all again? Absolutely. I couldn't not do it again. But I think had he known the costs, Terence would have fought the insurers spending enough, at roughly \$200,000, to vaccinate almost a quarter-million children in developing countries. That's how he would have thought about it.

Late last year, I waded through a snowstorm to Keith Flaherty's office in Boston, where he had moved to a new job that would let him intensify his work on targeted therapy. Did we help Terence? Or harm him? There's a possibility, he said, that the treatment actually made the cancer worse, causing it to rage out of control at the end. Or, as another doctor suggested in passing at the time, that the strokes were a side effect of the Sutent, and not the cancer.

Another Bell Curve

Flaherty and I looked at the numbers. The average patient in his trial got 14 months of extra life. Without any treatment, Flaherty estimates that for someone at Terence's stage of the disease it was three months. Terence got 17 months -- still within the realm of chance, but way, way up on the bell curve.

There's another bell curve that starts about where Terence's left off. It charts the survival times for patients treated not just with Sutent, Avastin and Nexavar but also Novartis's Afinitor and GlaxoSmithKline Plc's Votrient, made available within the past three years. Doctors and patients now are doing what we dreamed of, staggering one drug after another and buying years more of life.

Slides on the results of the clinical trial, presented at the 2008 meeting of the American Society of

Clinical Oncology, showed that Avastin and Nexavar worked well on a wide variety of patients. Only Flaherty and I know that the solitary tick mark at 17 months was Terence.

Only I know that those 17 months included an afternoon looking down at the Mediterranean with Georgia from a sunny balcony in Southern Spain. Moving Terry into his college dorm. Celebrating our 20th anniversary with a carriage ride through Philadelphia's cobbled streets. A final Thanksgiving game of charades with cousins Margo and Glenn.

And one last chance for Terence to pave the way for all those other poor sonsabitches.

----With assistance from Charles R. Babcock in Washington and Marybeth Sandell in Stockholm.

Editors: [Robert L. Simison](#), [Anne Reifenberg](#)

To contact the reporter responsible for this story: [Amanda Bennett](#) in New York at Abennett6@bloomberg.net

To contact the editor responsible for this story: Robert Blau in Washington at rblau1@bloomberg.net.

©2010 BLOOMBERG L.P. ALL RIGHTS RESERVED.