

Fighting to live, remain insured

"I am dying."

Those were the first three words of the e-mail Christine Lilly sent me.

"Or that's what they tell me," she continued. "But then, aren't we all?"

When I went to meet her, Lilly was reclining at the end of a long row of chemotherapy stations at a UCLA medical clinic in Santa Monica. Ten patients sat against windows, medicine dripping into their bodies as they gazed at the life surging past on Santa Monica Boulevard.

Lilly, a former schoolteacher in the midst of her fourth round of fighting inflammatory breast cancer since 2004, is in a clinical trial. At 57, she's not ready to close her eyes and go quietly, even if it means spending half of each day fighting for health insurance.

"I just can't believe this," the Westchester resident said in that e-mail, in which she talked about the high cost of staying alive. "I have a lot of guilt already about the financial position that I have put my family in."

Her white cell count was too low to handle much medicine the day I visited, so she finished before her son arrived to pick her up. She got rid of her own car as part of the scaling back she's had to do to pay the COBRA insurance, which is running her \$500 a month.

Lilly knows she is luckier than a lot of people. She at least has insurance. And she has no complaints about the care she has received. But she's tired of wasting precious energy researching the mind-numbing vagaries of Medicare, private insurance, medical disability, state COBRA, federal COBRA, etc., etc., etc.

She kept teaching second and third grades as long as she could at a Los Angeles elementary school, but finally had to give up a career that was interrupted over the years by the birth of four children and her husband's job transfers. The federal COBRA coverage dries up at the end of this month, she said, and she's trying to get an extension through L.A. Unified.

If that doesn't work, she'll apply for an 18-month state-run COBRA extension. But that one would cost her \$800 monthly, she said, and wouldn't include dental or vision care.

"And I've got a lot of dental damage from the treatment," she said.

If she's lucky enough to survive another 18 months, she doesn't know what she'll do.

"I'm uninsurable and I'm terminal, for Pete's sake. Even at \$800 a month, we're going to

be living paycheck to paycheck, trying to live as normal a life as possible. But normal is hard to hold onto."

Lilly's husband, an aerospace engineer, lost his benefits after a merger. He managed to find another job with benefits for both himself and his wife, but he's a contract employee who could be out the door any day, so Lilly can't risk counting on his insurance to keep her alive.

"It's sad to see people have to jump through so many hoops," said James Roh, a law student working at the Cancer Legal Resource Center at Loyola University's law school.

Roh, who tried his best to guide Lilly through the healthcare morass, said he is endlessly amazed at the stories of the several thousand cancer patients who call for help each year.

Roh said he recently had a case involving a man who was paying all his wife's medical bills and insurance premiums by credit card, and her insurance was canceled the moment his card was maxed out.

John Barstis, Lilly's oncologist, said he's seen it all too. He's had patients recover only to find that their jobs have been changed or eliminated, or their health insurance denied, dumping them into "punitively expensive COBRA or high-risk insurance programs.

"Congress did this so people would be able to get insurance, but it didn't legislate the price, so the cost is astronomical and then it runs out," Barstis said. "It's why we need universal healthcare. I think it's disgusting."

Of Lilly, he said: "She's had to fight and claw to stay alive, and she's done a great job of it."

The trial she's in won't cure her, Barstis said, but it has greatly diminished the cancer for now.

Such treatment is outrageously expensive, he added, which raises the always-uncomfortable question of what should be done, and at what public cost, to keep people alive.

It's fair to ask that in the case of an elderly person with a terminal condition and mounting Medicare bills, Barstis said. But because of medical breakthroughs, oncologists are able to add several years to the lives of their patients.

"Sometimes you have people with 5-year-old kids who want to fight for every day," he said.

Or people like Lilly, whom he called "a force of nature" with a strong will to live.

Lilly has some advantages. Her husband's income is good for now and they own some property they can sell if forced to raise money for medical bills.

But the question for all of us is this:

What kind of society builds obscene profit into healthcare, makes medical insurance a luxury, replaces secure pensions with risky 401(k)s and saddles its hard-working citizens with doubts and fears about being able to afford their most basic needs as they grow old? Something to think about when you vote for president this year.

Lilly is too busy surviving to follow the ins and outs of campaign trail promises on healthcare reform. She believes, simply, that all people should have access to the care they need.

She looked out the window at the schoolchildren who were playing with energy enough to make a sick former teacher feel young. A smile grew across her face.

"I still volunteer at my church," she said, and she looks after an elderly friend when she can, plays beach volleyball now and then, and loves to travel. "I still volunteer at my school too. God must have something more for me to do here."

The longer she's alive, Lilly said, the longer she can spread the word on preventive treatment. When she first noticed a change in coloration on her breast, and then a rash, a nurse told her by phone that it didn't sound serious. By the time she was examined, six weeks later, the cancer was so advanced she feared that she wouldn't last more than a few months.

"Life is good," said the teacher watching the children race around the schoolyard as if they'd never stop.

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