

The Health Care Crisis Hits Home

When my brother got sick and his insurers refused to pay, he needed help. After a dizzying, infuriating trip through the system, here's how we found it

BY KAREN TUMULTY/SAN ANTONIO

WHEN YOU'VE BEEN STRONG and fit your whole life, it can be easy to discount your body's first whispers of sickness as merely the side effects of daily living. Looking back over the past three years, my older brother Patrick now understands the meaning of his increasingly frequent bouts of fatigue, his fluctuating appetite and the fact that his blood pressure had crept up to 150/90. But Pat had always put off going to the doctor until he had to. Having bought health insurance that carried a \$2,500 deductible, he knew he would have to pay for a checkup himself. That is no small consideration for someone who makes \$9 an hour, as my brother did in his job as an administrative assistant for a lighting firm in San Antonio. He also struggles with Asperger's syndrome, a disorder sometimes described as high-functioning autism. Pat can multiply three-digit numbers in his head with ease, but he has trouble accepting the unfamiliar and adjusting to the unforeseen.

The unforeseen was exactly what turned up when Pat went in for a physical on Nov. 30, 2007, his first in five years. The doctor found high levels of blood and protein in his urine, results that were confirmed in another round of tests in December. Soon after that, Pat discovered that his urine had turned brown and foamy. In the middle of all this, he was laid off from his job, and finding a new one while doing temp work was his most pressing concern. Finally, last July my brother's doctor insisted that he see a specialist, who quickly ordered a biopsy. That's when Pat, who is now 54, learned that his kidneys were failing.

The diagnosis was only the first shock. The second came a few weeks later, in an Aug. 5 letter from Pat's health-insurance



The author and her brother

In a 1963 family photo, above, Karen and Patrick Tumulty are dressed for their First Communion. At right, Pat with his medication and his bills

company. For six years—since losing the last job he had that provided medical coverage—Pat had been faithfully paying premiums to Assurant Health, buying a series of six-month medical policies, one after the other, always hoping he would soon find a job that would include health coverage. Until that happened, “unexpected illnesses and accidents happen every day, and the resulting medical bills can be disastrous,” Assurant’s website warned. “Safeguard your financial future with Short Term Medical temporary insurance. It provides the peace of mind and health care access you need at a price you can afford.”

Kidney failure would seem to be one of those disastrous “unexpected illnesses” that Pat thought he was insuring himself against. But apparently he was wrong.

When my mother, panicked, called to tell me that the insurance company was refusing to pay Pat’s claims, I told her not to worry; bureaucratic mix-up, I assumed. I said I’d take care of it, bringing to bear my 15 years of experience covering health policy, sitting through endless congressional hearings on the subject and even moderating a presidential candidates’ forum on the issue.

Confident of my abilities to sort this out or at least find the right person to fix the problem, I made some calls to the company. I got nowhere. That’s when I realized that the national crisis I’d written so much about had just hit home.

The previous four weeks had left my brother with more than \$14,000 in bills from hospitals, doctors and labs. And that was just to figure out what was wrong with him. Actually treating his disease was going to be unimaginably more expensive. Patrick needed help quickly, and we didn’t have a clue where or how to start looking for it.

The Underinsured

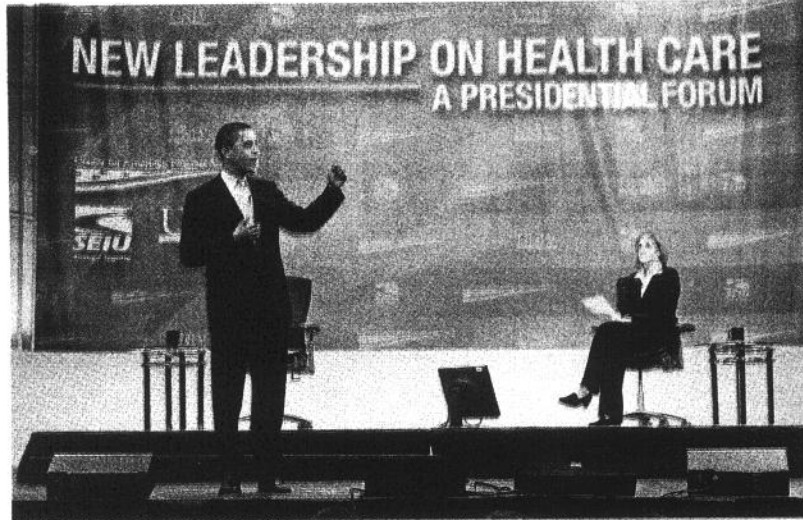
WHEN WE TALK ABOUT HEALTH-CARE reform, we usually start with the problem of the roughly 45 million (and rising) uninsured Americans who have no health coverage at all. But Pat represents the shadow problem facing an additional 25 million people who spend more than 10% of their income on out-of-pocket medical costs. They are the underinsured, who may be all the more vulnerable because, until a health catastrophe hits, they’re often blind to the danger they’re in. In a 2005 Harvard University study of more than 1,700 bankruptcies across the country, researchers found that medical problems were behind half of them—and three-quarters of those bankrupt people actually had health insur-

ance. As Elizabeth Warren, a Harvard Law professor who helped conduct the study, wrote in the *Washington Post*, “Nobody’s safe ... A comfortable middle-class lifestyle? Good education? Decent job? No safeguards there. Most of the medically bankrupt were middle-class homeowners who had been to college and had responsible jobs—until illness struck.”

If there is a ground zero for both problems, it is Texas, where I grew up and where my parents and brothers still live. About 1 in 4 Texans is uninsured, the highest rate in the country. The vast majority of the uninsured—8 in 10—live in households in which someone works, typically for a small business. But only 37% of Texas companies with fewer than 50 employees offer medical coverage.

The state’s Medicaid program is notoriously stingy. State law requires counties to provide care only to those deemed “indigent,” defined as people who earn less than 21% of the federal poverty line, or \$2,274 a year for a single adult and \$4,630 for a family of four. Many counties, particularly rural ones, do no more than that minimum. So Texas—a state with relatively little regulation of the health-insurance industry—is fertile territory for insurance companies selling bare-bones coverage at low prices.

But falling ill without adequate insurance leaves you at risk no matter where you live. Since 2005, the American Cancer Society (ACS) has maintained a national call center for cancer patients struggling with their bills. In that time, more than 21,000 people have called in asking for help. Every story is different, but the contours of the problem tend to be depressingly similar: the 10-year-old leukemia patient in Ohio who, after three rounds of chemotherapy and a bone-marrow transplant, had almost exhausted the maximum \$1.5 million lifetime benefit allowed under her father’s employer-provided plan; the Connecticut grocery-store worker who put off the radiation treatments for her Stage 2 breast cancer because she had used up her company plan’s \$20,000 annual maximum and was \$18,000 in debt; the New Hampshire accountant who, unable to work during his treatment



for Stage 3B stomach cancer, had to stop paying his mortgage to afford a \$1,120 monthly premium for coverage with the state’s high-risk insurance pool.

What makes these cases terrifying, in addition to heartbreaking, is that they reveal the hard truth about this country’s health-care system: just about anyone could be one bad diagnosis away from financial ruin. Most people get their coverage where they work. But Anna McCourt, a supervisor at the ACS call center, says employees often have difficulty understanding the jargon in insurance policies. Even human-resources personnel may not fully understand all the intricacies of a policy when briefing a new employee. Coverage that seems generous when you are healthy—eight annual doctor visits or three radiation courses—quickly proves insufficient if you find yourself really sick.

Between Coverage and Safety Net

PAT’S DECISION TO SAVE SOME MONEY BY buying short-term insurance was a big mistake, says Karen Pollitz, project director of Georgetown University’s Health Policy Institute and a leading expert on the individual-insurance market. “These short-term policies are a joke,” she says. “Nobody should ever buy them. It is false security that is being sold. It’s junk.”

Patrick’s support network

Sister Karen, above, moderating a forum in 2007; payment coordinator Deborah Haile, right, who confronted his insurer; social worker B.J. Smith, below, who guided him to CareLink



That’s because diagnosing and treating an illness may not fall neatly into six-month increments. While Pat had been continuously covered since 2002 by the same company, Assurant Health, each successive policy treated him as a brand-new customer. In looking back over Pat’s medical records, the company noticed test results from December, eight months earlier. Though Pat’s doctors didn’t determine the precise cause of the problem until the following July, his kidney disease was nonetheless judged a “pre-existing condition”—meaning his insurance wouldn’t cover it, since he was now under a differ-

TOP LEFT: STEVE MARCUS—REUTERS/LANDOV

HEALTH-CARE CHECKUP

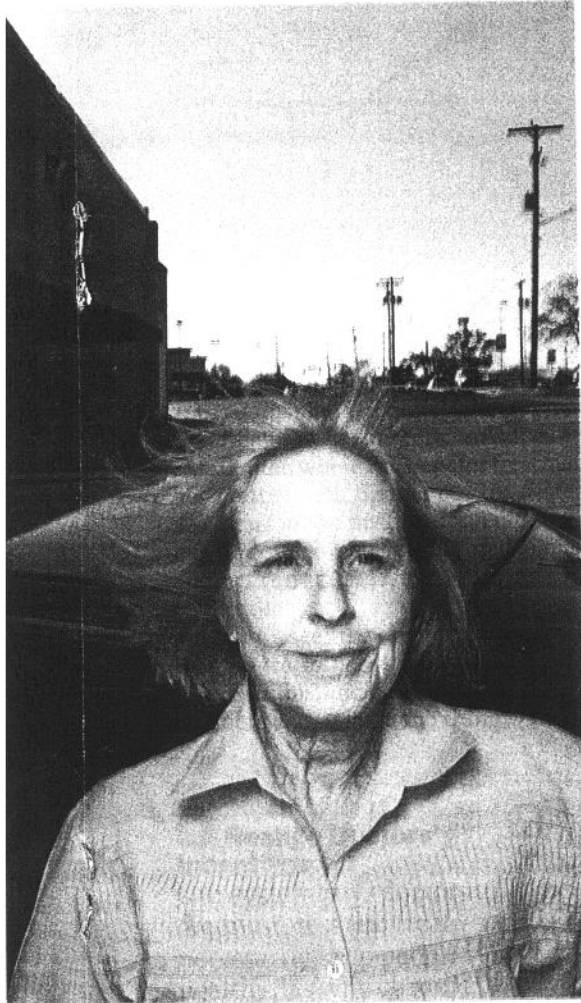
5 Priorities for Health-Care Reform

1 Cover Everyone: It’s Cheaper

When the uninsured seek care, they typically arrive sicker and require far more resources than the insured. So the U.S. spends more per capita than other nations—with less impressive results.

2 Prevention Beats Intervention

From prenatal to geriatric care, prevention pays. One easy example: widely available free screening for colon and breast cancer alone could save thousands of lives and billions of dollars annually.



TOP: LEFT: STEVE NARCUS—REUTERS/LANDOV

have to worry about, Haile assured me. Pat's kidney doctor, Peter Smolens, would keep treating him even if he couldn't pay. Smolens, a thin, soft-spoken man, later told me that about 10% of his patients have inadequate insurance or none at all. He has agonized with some as they struggled with hard choices, like whether to have a hospital biopsy or pay their mortgage. As a physician, he said, "you just see them. You know you're not going to get paid."

As grateful as we were for Smolens' forbearance, that still left us with the question of how to keep up with the rapidly mounting bills for drugs and lab work. Haile put us in touch with B.J. Smith, a social worker at the center. Patient and reassuring, Smith turned out to be the angel we needed. She had only recently returned to work after taking off seven years to stay home with her two children. The first thing she advised Pat was to start paying his bills, all of them, even if it meant putting down only a few dollars a month on each one. Otherwise, everything he had—his one-bedroom condominium, 2003 Saturn Ion and \$36,000 in savings—would be put at risk, as the letters from collection agencies had begun to arrive. Smith called Pat's medical creditors one by one and set up the arrangements: \$51.89 a month to one hospital, \$76 to another, installments of \$4.78 a month to \$111.89 a month on six different sets of LabCorp bills. Then there was the \$626 he owed two radiologists. One agreed to knock off \$22 as a hardship discount, writing Pat, "We are happy that we could be of assistance to you and your family in this time of need."

A paradox of medical costs is that people who can least afford them—the uninsured—end up being charged the most. Insurance companies, with large numbers of customers, have the financial muscle to negotiate low rates from health-care providers; individuals do not. Whereas insured patients would have been charged about \$900 by the hospital that performed Pat's biopsy (and pay only a small fraction of that out of their own pocket), Pat's bill was \$7,756. For lab work—and there was a lot of it—he was being charged as much as

six times the price an insurance company would pay. One pathology lab's bill alone was \$3,290.

Over time, with Smith's guidance, Pat learned to trim his bills here and there. Instead of refilling small prescriptions, for instance, he could buy some drugs more cheaply in bulk. (A hundred pills of one blood-pressure medication was less than \$16 at Costco, compared with \$200 at the pharmacy.) But that didn't address the cost of his care going forward. Pat's kidney function, which was 48% when Smolens first saw him last summer, has fallen to between 35% and 40%. And there are now outward, obvious signs of Pat's illness: he is lethargic, his eyes are puffy, and his lower legs and ankles are swollen to twice their normal size.

The disease—whose cause Pat's doctors doubt they will ever know—is winning. Now Smolens is trying to figure out whether Pat, whose Asperger's gives him a low tolerance for the demands of a complicated medical regimen, should move from his current medications to a more aggressive approach that includes immunosuppressing chemotherapy drugs. The newer drugs can cost \$10,000 a treatment; even the old ones can easily run \$500 a month. "It's almost like a black hole in terms of the potential costs," Smolens told me. "But when you look at the alternative—progressive kidney failure—then you're talking about having to receive dialysis, and the average cost of dialysis treatments in this country is \$60,000 per year plus."

There's another paradox: if Pat gets sick enough to need dialysis, as he well may, the Federal Government will pick up those staggering costs under the Medicare program for end-stage renal disease. But until that point is reached—and the goal is to keep him from getting there—his options are limited. Now that he is sick, it would be nearly impossible for him to purchase another insurance policy on the individual market. Since he lives independently and holds a job, it would be difficult for him to qualify for Social Security disability benefits. While Texas, like 34 other states, has a high-risk pool for those who

ent six-month policy from the one he had when he got those first tests.

After 33 years of wrestling with insurance companies, Deborah Haile, payment coordinator at the San Antonio Kidney Disease Center, where Pat went for treatment, has pretty much figured out the system. So when I put in my first desperate call to her, on Aug. 20, 2008, she offered to make another run at Assurant. Within an hour, Haile called back, her voice bristling with anger. "Cancel that policy," she advised me. "Your brother is wasting his money on premiums, and he's going to need it."

There was at least one thing we didn't

● **Realign Doctors' Incentives**

Our system pays doctors to diagnose, test and treat—not necessarily keep people healthy. It's why chronic diseases like diabetes absorb 80% of our health-care dollars. Pay for holistic success.

● **Reinvent the Hospitals**

There are too many medical "cafeterias," which fragments value and hurts quality, says Harvard's Michael Porter. Some hospitals should exit the transplant field, for instance, so the better ones thrive.

● **Go Paperless**

Like George W. Bush, Barack Obama is trying to make electronic health-care records the industry standard. Benefits: fewer prescription errors, risky drug interactions and duplicate tests; huge savings.

are hard to insure, the program is twice as expensive as an average individual health-insurance policy. And my brother would have to wait 12 months to join with a pre-existing condition, under the state's "adverse selection" regulations that seek to prevent uninsured people from joining the pool only after they get sick.

As we were running out of options, Smith told us there was one more avenue to try. Bexar County—where San Antonio is located and an estimated 30% of people under 65 do not have health coverage—has a health-care program for the uninsured that is far more generous than most in Texas and practically unique in the country. Rather than continuing to wait for the uninsured to show up in its emergency rooms, in 1997 the Bexar County hospital district established a system called CareLink for those who make 200% of the poverty line or less. (In his current job, answering queries that come in to a text-message information service, Pat earns \$1,257 a month, which means he qualifies.)

CareLink operates much like a health-maintenance organization for its 55,000 clients, negotiating prices with health-care providers and then billing clients on a sliding scale according to their income. (Pat's CareLink bills run around \$40 a month.) And it puts a heavy emphasis on preventive care; on Pat's first examination at an austere CareLink clinic in northwestern San Antonio, he got tetanus and flu shots as part of the deal. Another stroke of good fortune: Pat's kidney doctor, Smolens, is a participating specialist with CareLink.

For primary care, CareLink assigned Pat to Dr. Carolyn Eaton, an engaging woman who has been working with the system for about a year. What alarms her most about the new patients she has seen lately, Eaton says, is how long people wait—diabetics whose feet are numb, cancer patients already in the advanced stages of the disease—before they seek treatment. "When people fall on hard times, they're kind of embarrassed," Eaton says. "Their health care ends up becoming much more expensive."

It's not a seamless system. Pat gets confused navigating between Smolens, who prescribes tests and medications, and CareLink, which must approve them. "The fact is, for guys like Pat, it requires a lot more work to do the same sorts of things" that would be a snap if he had insurance, says Smolens, sighing.

The Limits of Personal Choice

AS THIS COUNTRY PREPARES TO ENGAGE in its first serious debate over comprehensive health-care reform in 15 years, there are two leading approaches to covering the 45 million uninsured and reining in

costs. One, which President Barack Obama is putting forward, would force more employers to offer coverage to their workers, with subsidies and other incentives to make it more affordable. The other, advocated by Republicans (including Senator John McCain in the recent presidential campaign), would take away some of the tax advantages that come with getting coverage at work and thereby put many Americans who are now covered by their employers into the marketplace on their own. The idea is that they would be the ones best equipped to decide which plan suits their individual needs.

Pat's experience suggests it is difficult for an individual to make such judgments. And the existing market for these kinds of policies leaves a lot to be desired. A 2006 Commonwealth Fund study found that only 1 in 10 people who shopped for insurance in the individual market ended up buying a policy. Most of the others couldn't find the coverage they needed at a price they could afford.

The individual health-care consumer has very little power or information. Still, it turns out that there are ways to fight

INSURANCE CHECKUP

Are You Underinsured?

Twenty-five million Americans pay for health insurance but have inadequate coverage. There's no magic formula for figuring out how much coverage is enough, but here are a few pitfalls to avoid:

High deductibles. A 2007 Commonwealth Fund report found that 25% of the underinsured pay annual deductibles of \$1,000 or more, a red flag for scant coverage.

Caps or omission of services. Read your plan to check for limits on drug coverage or per-day hospital fees, which may leave you with bulging health-care bills.

Temporary or short-term policies. Buying into these plans may disqualify you from comprehensive long-term coverage later, especially if you have a pre-existing condition.

Serial short-term policies. Each successive policy you purchase treats you as a new beneficiary, so changes in your health may later be considered a pre-existing condition.

—BY ALICE PARK

The waiting room After his insurance company refused to cover his kidney disease, Patrick Tumulty found care he could afford through a program run by the county hospital system

back. As I was reporting my brother's story, I discovered something about Pat's former insurance company: last May, insurance regulators in Connecticut imposed a record \$2.1 million in penalties on two Assurant subsidiaries for allegedly engaging unfairly in a practice called post-claims underwriting—combing through short-term policyholders' medical records to find pretexts to deny their claims or rescind their policies. In one case, a woman whose non-Hodgkin's lymphoma was diagnosed in 2005 was denied coverage because she had told her doctor on a previous visit that she was feeling tired. Assurant agreed to pay the fine but admitted no wrongdoing.

So I contacted the Texas Department of Insurance, identifying myself as both the sister of an aggrieved policyholder and a journalist. Officials there suggested that Pat file a complaint against the company. Each year the department receives as many as 11,000 complaints and manages to get \$12 million to \$13 million back for consumers, Audrey Selden, the department's consumer-protection chief, told me. "It is important to complain."

And it's easy too. It took Pat and me less than 10 minutes to fill out the complaint form over the Internet. That was Jan. 14, 2009. On Feb. 9, we had an answer: Assurant maintained that it had done nothing wrong and that Pat should never have relied on short-term coverage over a long period. But given "the extraordinary circumstances involved," the company agreed to pay his claims from last year, when the policy was still in force. (Pat canceled it on Aug. 22, 2008.) Those extraordinary circumstances, I assume, included the fact that the state insurance department was sniffing around.

After we received the insurance company's decision, I tried to talk to Assurant for this story. Its only response was a written statement from Scott Krienke, senior vice president for product lines: "Due to privacy regulations, we cannot discuss the specifics of any of our customers' coverage." But he also noted that "Assurant Health's Short Term Medical product is designed for people experiencing a break in the continuity of their permanent medical coverage. Our Individual Medical plans are more appropriate for those who have an ongoing need for medical coverage."

I wish the company had told my brother that when it sold him the policy in the first place. ■