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*From the Los Angeles Times*

## Coverage, in pieces

**Medical insurance can be surprisingly elusive -- and temporary. For many, the safety net now requires compromise and sacrifice.**

By Susan Brink

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HEALTH insurance coverage is cyclical. It changes with age, jobs, income, marriage, divorce — even with sickness itself.

Some stories of what people do to stay covered are whispered in confidence: a marriage of convenience, a divorce put on hold, a person too sick to work kept on the payroll by a compassionate boss.

Others are more obvious: a hated job held onto; retirement ruled out because a worker, or the worker's spouse, is not yet 65 and, therefore, ineligible for Medicare; an economically comfortable couple, thriving on one self-employed income, sending the other spouse to a 9-to-5 job for the health insurance.

The nation's political, business and community leaders are all grappling with the escalating cost of healthcare. But it's not just Medicare and Medicaid budgets that cause concern in the public discourse. Events that once may have been seen as unrelated corporate decisions, such as layoffs at General Motors, are readily linked to the problem of rising healthcare costs.

Among the general public, there is a gnawing uneasiness that anyone, at any time, is a pink slip away from joining the ranks of the uninsured.

But it can happen even without the pink slip. A good job used to mean good health insurance. Since 2001, employees' share of health insurance costs has risen 58% for family coverage, 63% for single coverage. Working people who can no longer afford the bite out of their take-home pay become uninsured. And more companies are dropping health benefits altogether. Today, only 61.9% of working people get coverage through their employers, according to the Kaiser Family Foundation, down from 71% in 1987.

In discussion groups around the country, called for by Congress in a little-noticed

provision of the Medicare Modernization Act of 2003, individuals are talking about their worries. A meeting was held last month in Los Angeles, and about two-dozen similar town hall-style meetings are scheduled for other cities. In the fall, these opinions will be added to a mix of reports Congress will receive summarizing meetings held in 36 cities, as well as survey results received on the Internet ([www.citizenshealthcare.gov](http://www.citizenshealthcare.gov)).

"I think many people are starting to feel the slipping-through-the-cracks phenomenon, that it could happen to them," says George Grob, executive director of the Citizens' Health Care Working Group, which is organizing the meetings. "In general, people worry about the cost of care, about access to care for themselves, and for everyone else. A common theme is that it's time to do something about it."

Congress is committed, if not to act, at least to listen.

The stories in this package illustrate the obstacles encountered, as well as the generous doses of creativity required, as people cobble together health coverage in America's often hit or miss system.

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(INFOBOX BELOW)

The changing face of coverage

PEDRO BARRERA

WHEN a bundle of cardboard boxes headed for the recycling bin fell off a forklift in February 2001 and hit Pedro Barrera, 50, the blow sent him flat on his back and, ultimately, out of the workforce.

At the time he was insured through his employer, Macy's. "I paid \$30 a week," he says. But he couldn't afford to insure his whole family, including three children. "They wanted \$150 a week. That's a lot of money," he says. He lost his own coverage when he lost his job.

Since the accident, Barrera, a permanent resident in the United States, has bought insurance through the national health system in Mexico — paying \$175 a year for medical, dental and vision coverage. When Barrera needs care, he heads south. "When I need to go to the doctor, I take a trip to Tijuana," he says.

"I am worried," he says. "Not only for myself, but for the whole community. I come from South Central, and probably 90% of the people there don't have insurance. They don't have access to visit the doctor. It's too expensive. So usually they go to USC hospital."

When they go to the Keck School of Medicine at USC, they are not turned away. The hospital has a contract with the L.A. County health department, and although the public dollars don't cover the full cost of uncompensated care, it makes the hospital the biggest

provider of care to uninsured people in the county.

About 50% to 60% of outpatient visits are from people without insurance, says Jeffrey Huffman, dean of clinical affairs at the medical school, and 40% to 45% of emergency visits. "We take care of them, regardless of their ability to pay, as they present themselves," he says. "A patient is a patient."

Some, like Barrera, do what they can outside the healthcare system to avoid illness. He is a volunteer for a project he hopes will help keep members of his community healthy: the South Central Community Garden.

The garden has flourished on 14 acres of land on Alameda Street for a generation of gardeners. Although the land's owner, Ralph Horowitz, recently won a court battle to evict them, a new garden, on 111th Place and Stanford Street, opened for planting March 26. Barrera expects it to thrive not only with carrots, lettuce and tomatoes, but also with herbs and medicinal plants.

"In our culture, we have in our mind that everything comes from the plants," he says. "We have all kinds of plants for problems with the stomach, with diabetes. You don't see these plants in the markets. All of the plants are something for health."

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#### GEOFF CUNNINGHAM AND NICOLE SMITH

GEOFF CUNNINGHAM'S sporadic health insurance history is so very Hollywood. When he's hot, he's hot. And when he's not, he's uninsured.

"It just depends on your income, and in entertainment, it fluctuates," says the 36-year-old filmmaker. "When you don't have much coming in and you're thinking about what might get cut, you start thinking, 'Well, I'm relatively young and healthy.' There have been times in my life when I've chanced it. My parents freak out."

Chancing it means going uncovered, betting that unexpected disease or injury will not hit. For most of his adult life, his insurance status has depended on the work he's doing and for whom. He's had permanent jobs and with them he's been covered by a variety of plans, including HMOs and PPOs. He's run his own business during which, at times, he and his wife, actress Nicole Smith, have taken the risk of going without health insurance. At one point, Smith had to go to the emergency room for heart palpitations that turned out to be nothing more than a scare.

"They ran a few tests, and the bill was a couple of thousand dollars," says Cunningham. The West Hollywood couple paid out of pocket.

Coverage for a lot of Americans is spotty. The U.S. Census Bureau reports that nearly 46 million Americans didn't have health insurance in 2004, but like Cunningham, many of them go in and out of the market. Some 73% of those uninsured have gone without

coverage for at least a year, while 27% have been uninsured for less than a year.

Now, Cunningham and Smith have decided to buy a health insurance plan that costs \$1,250 a year for both of them, but covers nothing until a \$10,000 deductible has been met. The conker, he says, is how difficult it is to know what you're buying in the individual health insurance market. "What I hate about this is you can't shop for it, you can't compare what you'll actually be getting. There's no transparency," he says. Still, he knows he's lucky. If the worst happened and he and his wife had to come up with \$10,000 for medical bills before coverage kicked in, they could manage it. "A lot of people couldn't take that hit," he says.

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### MAMIE JACKSON

MAMIE JACKSON has been working her way through the bureaucratic red tape of private and public insurance since her kidneys failed in 1990.

A federal law helped the Studio City woman, now 51, qualify under Medicare for coverage of the dialysis she needed for several years and for the kidney transplant she received in 1996. "I'm not a senior, but once you go into kidney failure, Medicare kicks in," she says.

Kidney failure has been covered by Medicare since 1972, shortly after Shep Glazer, a kidney dialysis patient, was wheeled on a gurney into the House of Representatives where he testified before a committee — while being dialyzed. Shocked that such care was being denied to patients who could be saved, Congress passed the End Stage Renal Disease amendment to the Medicare Act, and kidney patients became the first disabled people younger than 65 who could qualify for Medicare. Today, 6.7 million disabled people, in addition to 35.6 million elderly people, qualify for Medicare, according to the Centers for Medicare and Medicaid Services.

Before she had health problems, Jackson was upwardly mobile, moving from Southern segregated poverty to the world of academia. She has childhood memories of marching for civil rights with her mother in Mobile, Ala., facing off snarling dogs and meeting the Rev. Martin Luther King Jr. Her mother worked as a domestic employee after Jackson's father, a longshoreman, died in a dock accident.

Jackson and her five siblings, pushed by their mother, got good educations. "But I was the overachiever. I got several degrees," she says, the last one being a master's in organizational management from the University of La Verne.

At the time her disease hit, she was a professor at Cal State L.A. So in addition to Medicare for treatment of kidney disease, she had health insurance to cover the needed drugs.

But over the years, she got weaker and sicker, eventually giving up full-time work for consulting and buying her own health insurance. "The more ill I became, the more they

increased my premiums," she says.

Finally, she could no longer afford coverage. She began burning through her savings to pay for the thousands of dollars worth of drugs she needs every month to combat rejection of the transplanted kidney, and to treat high blood pressure and diabetes.

What she did is known as spending down — literally impoverishing oneself in order to qualify for Medi-Cal, the state health insurance program for the poor. A single person qualifies if monthly income doesn't exceed \$812 and assets total \$2,000 or less. With her medication bills, it wasn't hard to get to that level.

"Once I no longer had the HMO, I was paying retail," she says. "I take 27 drugs a day. It just wiped me out." Once she had nothing, Medi-Cal covered her drugs.

The coverage worked pretty well — until the new Medicare prescription drug benefit took effect Jan. 1. It provides limited drug coverage for people on Medicare. If those people previously qualified for state Medicaid programs, called Medi-Cal in California, they were switched to the federal drug plan. A March 21 report by the California HealthCare Foundation found that those people, called "dual eligibles" in bureaucratic-speak, have access to a narrower range of pharmaceuticals than they had before.

Again, Jackson is back to studying her options.

She has taught, written, sung gospel and traveled extensively before coming full circle back to poverty. "I've adjusted my life to where I don't need a lot of money," Jackson says. Along the way up and back down the income scale, she's experienced just about every configuration of healthcare coverage available in America.

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## JIM JOHNSTON

JIM JOHNSTON met his wife, Frieda, in college in Nebraska, shortly after World War II. Those were days when tobacco companies had ad campaigns such as L&M's "Just what the doctor ordered," Camel's "More doctors smoke Camels than any other cigarette," and Viceroy's claim to provide "double-barreled health protection." Frieda Johnston, 82, smoked two packs of Pall Malls a day and didn't quit until 1988.

Two years ago, it caught up with her.

"She woke up and couldn't catch her breath," says Jim Johnston, 80, of Ogden, Utah. They were in Oceanside, where they spend the winter months each year, when the crisis hit. "We whipped into the emergency room, and while I was signing one piece of paper, they already started working on her," he says. She needed surgery for an aortic valve replacement, spent two weeks in the ICU and then suffered a terrifying cardiac arrest.

"They did CPR right on the floor, and then she went back to the ICU for two more weeks."

Finally, she spent two weeks in rehabilitation. She's been doing pretty well since.

As a senior, she was covered by Medicare, and the couple also has AARP Medicare supplementary insurance. "I walked out of there owing virtually nothing," says Jackson. "I think it was maybe \$400 for the whole mess out of my pocket.... I figure I've got one heck of a deal."

But only 42.4 million people qualify for Medicare, all either 65 and older or disabled.

Now, with the baby boom generation heading for retirement beginning in 2011 — and the new prescription drug benefit projected to cost \$558 billion through 2013 (according to the Congressional Budget Office) — many are debating when, not if, the program will be bankrupt.

Like so many Americans, Johnston doesn't know how the system can continue working as well for future generations as it has for him and his wife. He's particularly stumped by the medical cost demands at the very end of life. Between 27% and 31% of Medicare spending goes for care during the last year — often costly treatments that can add days, weeks or months to a dying patient's life, according to a December 2005 article in the journal *Health Affairs*.

"The ungodly cost of the last years of life ... ," he says. "I don't know how you deal with that."

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#### CYNTHIA La MORGESE

CYNTHIA La MORGESE is a nearly perfect health specimen: 29 years old, works out at least three times a week, eats vegetarian, practices Pilates.

"I answer 'no' to pretty much everything on the [health insurance] application," says the West L.A. woman. That is, no diabetes, no high blood pressure, no high cholesterol, no history of kidney disease. Surgeries, yes, one knee laparoscopy after an injury following a workout a few years ago. Smoking, no, not anymore; not after treatment with Wellbutrin, an anti-anxiety drug shown to help people kick the tobacco habit.

She works two jobs, one as a tutor for high school students, the other as a part-time clerk at the Venice Health Clinic. They add up to more than full-time hours, but neither job provides health insurance.

"I can't get insurance," she says. Her knee injury is noted as a preexisting condition when she applies. Her seven-year history of smoking and use of Wellbutrin are cited as reasons for a cost that's more than she can afford.

The best she could do was a plan that would cost \$120 a month, but it came with a \$1,500 deductible. She'd have to pay a monthly premium, plus every penny of every

appointment, medical test or prescription drug she could anticipate needing, since her yearly medical expenses would probably fall below \$1,500 a year. She paid for a couple of months, then dropped it because of the expense.

"People my age don't have insurance," La Morgese says. "We can't afford it."

Her parents' insurance covered her as a youth, and an adequate health insurance plan for students got her through studies at Columbia University. She'll head off to medical school in the fall and hopes to find health insurance as a student again. But for now, as a young working woman, she can't find a company that will sell her insurance for a price she can afford.

That's not uncommon, according to a 2002 Institute of Medicine report called "Health Insurance is a Family Matter." Researchers found that the age at which most young people leave home — and are dropped from their parents' health plans — is also the age at which they're at highest risk of being uninsured. In 2002, the uninsured rate for people 18 to 20 was 24.2%, climbing to more than 30% for those age 21 to 24, before dropping to 17% for people age 25 to 34.

"I'm a 29-year-old educated woman," La Morgese says. "I have a master's degree in forensic psychology, and when I'm sick, I get care at a free clinic. It's horrible, and I don't know what the answer is."

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#### GWEN LAUTERBACH

FOR 14 years, Gwen Lauterbach, 59, has been in a state of marital limbo, separated but not divorced. She's continued that lifestyle, with the amicable cooperation of her estranged husband, for as long as she has not because of inertia, ambivalence or religion. "We've stayed married so that I could have health insurance," she says.

When they decided to split in 1992, Lauterbach was not working and was insured through her husband's policy. The jobs she had held included freelance writing gigs, which don't come with health insurance, and positions with small, nonprofit organizations, notorious for budgets too stretched to provide employees with coverage.

"I probably could have found some kind of job, but it wouldn't have come with insurance. So we just drifted along this way and didn't bother with divorce," she says.

Until about three years ago, the fear of going without coverage was largely hypothetical. Then, at 56, she had a stroke. "It was this weird, out-of-the-blue thing. One side of my face started twitching. And that side of my body felt like I was coming out of Novocain," she says.

Now her medical history, a pre-existing condition, renders her uninsurable on the individual market.

About the time she was recovering from the stroke, she and her estranged husband began talking about a new wrinkle in the imperfect setup they had agreed to for more than a decade. Her husband, a few years older than Gwen, plans to retire soon. At 65, he'll qualify for Medicare coverage, but the federal program doesn't cover spouses.

So they switched to a backup plan. She started working for her husband's business, Lauterbach and Associates, an architectural firm specializing in affordable housing. It was a way she could get her own insurance coverage, and the couple could finally move forward on a divorce, which they are doing, and go their independent ways.

"One of the things that continues to bother me is how tied [health insurance] is to employment," she says. "What we've done is perfectly legitimate. But on the other hand, I probably wouldn't be working at the company with my ex-husband if it weren't for health insurance."

After more than a decade of being tied to a marriage for the health insurance, she is now tied to a job for the same reason, limping toward the Medicare coverage years while hoping illness doesn't strike again and render her unemployable before she turns 65. "I love the company, but it's not what I would be doing if I didn't have to worry about insurance," the Oxnard woman says.

"I favor a single-payer system, taking health insurance away from being a condition of employment," she says. "How many people stay at jobs they hate because they're afraid of losing insurance?"

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