

The Families and Their Stories

"Lord, keep us well."

The Roberts Family, Bena, Virginia

"I constantly worry: What if something happens?"

The Cervantes and Zamora Families, Corpus Christi, Texas

"Sometimes there was insurance, and sometimes there wasn't."

The Nelson Family, Louisville, Tennessee

"I need some kind of help."

The Smith Family, Paterson, New Jersey

"I wanted to be able to take care of my baby."

The Combs Family, Hemet, California

"I barely get finished paying one bill when the next one comes in."

The Mendivil Family, Tucson, Arizona

"Is there something else I should be doing?"

The Taylor Family, Guthrie, Oklahoma

"Sometimes I feel like I'm 90 years old."

Dianna Oden, Mosier, Oregon

The Roberts Family, Bena, Virginia

Note: Out of respect for changed circumstances and personal privacy, we have concealed the true identity of one of the families. Although their names and location are fictional, their experiences remain true and typical of many families in America.

“Lord, keep us well.”

Married in their teens, Thomas and Virginia Roberts managed to beat the odds, building a warm and supportive relationship that’s lasted 28 years. They’ve raised four strapping sons, three of them college graduates and one just starting his freshman year.

Through the years, Tom, now 46, has worked hard to provide for his family. He’s worked at lots of different jobs—as an assistant minister, a sheet metal fabricator, a Hawaiian Punch can assembler, a machine mechanic, a painter, and a construction supervisor—acquiring so many skills along the way that he was able to build four of his family’s homes.

Not all of those jobs provided him with health insurance, though. In fact, he and the family often weren’t covered. They paid for health care as they needed it and put off what they could.

"We used to pray about it. 'Lord, if you can't give us insurance, then keep us well,'" recalls Virginia, 45.

Fortunately, their boys had few health problems as they were growing up. When the family had health insurance, everybody got regular medical and dental checkups. When they didn't, the boys saw doctors only for immunizations and ear infections, and the parents generally saw no one at all.

Although many uninsured families seek care in emergency rooms when they're sick, the Roberts shunned them as much as possible because of the expense, instead paying up front for a consultation with a doctor when an illness made medical attention absolutely necessary. "We weren't that worried," Virginia says. "We figured we could handle it. We could pay the bills."

Then, two things happened—an injury and an illness—to shake their confidence.

In 1994, their third son, Timothy, broke his leg in a high school soccer game. The bills for the ambulance, the hospital, the orthopedist, and other expenses came to more than \$1,200. A few months later, he reinjured the leg in another soccer game, incurring \$600 in medical bills. "That started to make us afraid," says Tom. "Up to then, we had been blissfully ignorant."

The accident happened near the beginning of Tom's six-year stint with a small construction company that provided no health insurance benefits. Virginia had just begun working as a part-time driver for the Central Virginia Area Agency on Aging. She loved her job transporting senior citizens and delivering meals to the homebound, but it provided no health insurance benefits either. Together, the couple earned less than \$30,000 a year, not enough to buy insurance without an employer subsidy. The Roberts settled Timothy's medical bills by sending monthly payments for more than a year.

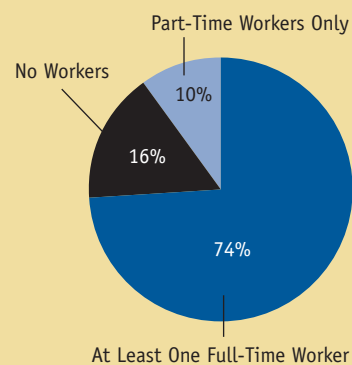
Three years later, their second son, Stephen, became terribly ill. His illness came at a bad time, since their budget was already stressed with tuition bills. They had already put their oldest son, Abe, through college, and were then paying college tuition for Stephen, a junior at nearby Liberty University, a Christian college. Timothy was also at Liberty, with his tuition covered by a scholarship guaranteed to graduates of a private religious secondary school. And the youngest boy, Daniel, was in high school at the same private school, hoping to qualify for a similar college scholarship, but, meanwhile, accumulating high school tuition bills. Each boy worked part-time to help pay his own expenses.

At first, Stephen complained about stomach problems. He thought he might have an ulcer. He saw a doctor, who dismissed his pain as muscle spasms.

But the symptoms got worse. He wasn't able to eat very much, vomited frequently, and lost weight. Frantic with worry, his mother called the only local gastroenterologist. "I was crying and very upset," she recalls. "I said, 'Someone had to help us.'" The doctor agreed to see Stephen the next day.

Most of the Uninsured Are in Working Families

44 Million Uninsured, Distribution by Family Work Status



Source: Urban Institute, estimates from the Current Population Survey, March 1999.

After hundreds of dollars worth of blood tests, X-rays and a biopsy, Stephen was diagnosed with Crohn's disease, a chronic inflammatory disease of the gastrointestinal tract. The disease causes abdominal pain, diarrhea, loss of appetite, anemia, and weight loss, and can be fatal.

It was then that the Roberts realized how much financial trouble they could land in without health insurance. In the past, they had always believed they could keep up with the medical bills for their family—and they had. Now the doctors were ordering more tests for Stephen. “All of the medical expenses together totaled several thousand dollars,” Virginia remembers, “and we were hit with things we could not keep up with.”

Stephen improved for awhile, but then relapsed. His mother, who had hardly ever taken a sick day from work for herself, would call in sick to care for her son. His father started looking for a job that would provide health benefits, but had no luck.

Worried about Stephen, and worried about being able to pay for his care, the Roberts subdivided their rural property near Lynchburg, Virginia, with its peaceful view of the Blue Ridge Mountains, and Tom began building a smaller house next door. Their plan was to move into the smaller house and try to sell the larger house so they could pay off their fast-accumulating debt.

Looking for help

As Stephen struggled to get well, only to relapse several more times, Virginia became fiercely involved with his care. Although it was inexpensive, the prednisone he was taking to control inflammation caused troublesome side effects, and Asacol®, another, more expensive medicine he was also taking, didn't seem to be doing him much good. Virginia began investigating alternative medicines, charging nearly \$1,000 worth of herbal remedies on her credit card.

During the summer of 1998, between his junior and senior years in college, Stephen took a job in New Jersey. On the Fourth of July, the Roberts got a worried call from Abe, their eldest son, who was attending law school in Washington, D.C. Stephen had become very ill again. Although he had managed to drive himself to his brother's apartment, he could go no further. His parents drove nearly 200 miles to bring him home.

“At that point, I was just so frustrated,” says Virginia. Listening to a doctor on a talk radio show one day, she was filled with hope when he mentioned promising research on Crohn's disease. Virginia tracked down the researcher in Texas, and he referred her to a doctor in Chapel Hill, North Carolina. She called him that weekend at home.

The following week, she and Stephen drove three hours to his office in North Carolina, and the doctor, who himself suffers from Crohn's disease, suggested that Stephen try a different drug, called Pentasa®, that had shown encouraging results in Crohn's patients.

“People do sometimes look at you differently. It's like a stigma, even though there are thousands of people who are uninsured.”

From the start of Stephen's illness, the Roberts had come face to face with a financial reality that confronts many families without health insurance—the high cost of prescription drugs. At the local K-mart, Pentasa® cost \$105 for a bottle of pills that lasted about 20 days. The pharmacist sold it to Virginia at a discount—\$96 a bottle—but Virginia had to put most of the cost on a charge card that was already accumulating burdensome finance charges. “We had no choice,” Virginia says. “Once you get behind with something, there’s a snowball effect.” After a few purchases of Pentasa®, Virginia managed to reduce the cost by driving nearly three hours to North Carolina, where the hospital’s pharmacy would sell her two bottles of Pentasa® for \$133, a \$59 savings.

Eventually, because of his status as an uninsured college student, Stephen was able to qualify for financial assistance for some of his medical care in North Carolina and Virginia, including the cost of the prescription medicine. (In addition, the gastroenterologist agreed to waive half his fee.) When the nurse at the North Carolina clinic sent the Roberts a letter with the news that Stephen had qualified for assistance, along with the first free package of his medicine, Virginia was so grateful that she sent the nurse a token of gratitude and friendship—a 60-minute telephone card and a book of stamps. When the family gets back on its feet, Virginia says she would like to give some money to the hospital that helped Stephen “so someone else could use it.”

Throughout Stephen's illness, Virginia did her best to spare her son the embarrassment of not having insurance. “When we went for office visits, I would pay then and there because I didn’t want to embarrass him,” she says. “People do sometimes look at you differently. It’s like a stigma, even though there are thousands of people who are uninsured.”

A stack of bills four inches high

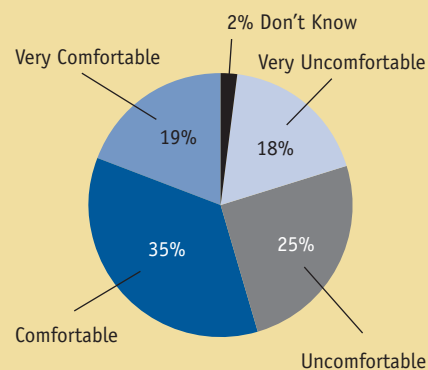
Stephen managed to finish college last year, despite his illness, and he is living and working in New Jersey. He has medical insurance through his job and is able to cover his own bills now. His condition seems to have stabilized. “He looks good,” his mother says, happily. “The Lord has been gracious in taking care of him.”

But his long medical ordeal resulted in bills stacked four inches thick on the Roberts’ coffee table. “My husband and I don’t like having debt,” Virginia says. “We live on what we make and take care of our bills.” However, the cumulative effect of medical bills and college tuition has made it impossible for them to stick to their pay-as-you-go principle. Two years after Stephen first became ill, the couple has reduced their medical debt to about \$2,500 by paying \$10 or \$25 monthly to each creditor. “The people are understanding,” Virginia says. “As long as you’re sending money every month, they don’t complain.”

Last February, the Roberts took the next step in their plan to regain financial stability. They moved into the new, smaller house that Tom built and put their original, larger house on the market to raise money to pay off their debts.

Many of the Uninsured Are Not Comfortable Telling Others They Are Uninsured

Degree of Comfort Telling Family and Friends They Are Uninsured



Source: *The News Hour with Jim Lehrer/Kaiser Family Foundation National Survey on the Uninsured, 2000.*

So far, they haven't found a buyer. "When we sell the house, we can pay off everything," Virginia says.

Today, Virginia and her youngest son, Daniel, 19, a freshman at George Mason University, are the only members of the family not covered by health insurance. Last year, Tom Roberts found a job that offered health insurance as a benefit, though he had to take a pay cut. He now works as a painter at Centra Health Virginia Baptist Hospital. But the employer only pays for *his* coverage. To cover Virginia and Daniel, their only remaining dependent child, Tom would have to pay \$240 a month. (The three oldest sons each work in jobs that provide insurance.) To cover Virginia alone, it would cost \$145 a month. With the couple's combined income still less than \$30,000 a year, and with the old medical and tuition bills they're still paying off, they can't figure out a way to buy coverage until—and if—they sell the second house.

Even though he has insurance for himself, Tom hardly goes to the doctor. "I have to be really, really laid out to go to a doctor," he says. "I would feel guilty using insurance if the rest of my family can't. I'd rather let it sit there. How could I say to them, 'Oh, yeah, I'm going to go get my dental needs taken care of, but you can't?'"

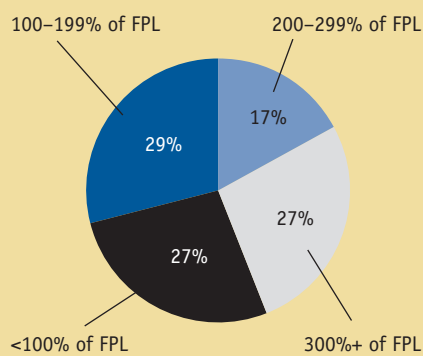
Virginia tries to compensate for not having insurance by being health-conscious. "I take care of myself," she says. "I eat right and exercise, and I try to maintain a proper weight." Although she was scrupulous about seeing a doctor while she was pregnant with each of her sons, the only times she's seen a doctor in recent years have been for a Pap smear and a painful sinus infection. Recently, she was forced to see a dentist when a piece of one of her teeth broke off. The dentist wouldn't accept monthly payments, so she had to save up first to pay the \$80 bill. "Now I need to save money to get my teeth cleaned," she says, smiling. "I want to keep my teeth!"

Virginia has been applying for full-time jobs with benefits at the hospital where her husband works. "I keep applying, and I've not got one yet," she says. To save money, she shops for bargains, even in health care. For instance, she takes advantage of a Health Awareness event at the local shopping mall to get her cholesterol, blood pressure, and vision tested. A few years ago, she found a \$10-off coupon in the newspaper for mammograms and used it, along with the cash her husband gave her for Christmas, to pay for a \$45 mammogram, her first ever. But the mammogram showed abnormal cells, and further tests were necessary. "What should have been a \$45 bill turned out to be several hundred dollars," she sighs. Virginia was advised to have a mammogram every six months, and has since found a local health department program, called Every Woman's Life, that provides free Pap smear screenings and mammograms to women without health insurance.

A recent illness of Daniel's illustrates the lengths to which Virginia goes to keep her family's health care expenses to a minimum.

Most of the Uninsured Have Low or Modest Family Incomes

44 Million Uninsured, Distribution by Poverty Level



Note: The 1998 federal poverty level (FPL) for a family of 3 was \$13,650

Source: Urban Institute estimates from the Current Population Survey, March 1999.

Daniel had returned from a wedding with a terrible sore throat and a high fever. He wanted to go to the emergency room right away, but his mother persuaded him to wait until morning, when they could go to a less expensive walk-in clinic. “Once you walk into the ER, they send you a bill for this and a bill for that,” his mother told him.

So Daniel got up before dawn the next day to be first in line at the clinic. He was diagnosed with strep throat and a bad case of mononucleosis. He paid the bill with his mother’s credit card.

The Roberts took this new medical problem in stride. They’ll pay the bill just as soon as they can, because they see it as their responsibility. They don’t believe they’re owed anything—not by the government, not by employers.

“It’s my private responsibility”

But Tom would like to see companies take more responsibility for their employees. He remembers what it was like growing up in New Jersey, where his father, a union electrical worker, always had good employer-provided health insurance for his whole family. Tom also remembers his own experiences with employers that provided good coverage. “We were well taken care of,” he recalls. But as time went on, those kind of jobs have become harder to find.

“It may be wrong on my part,” he says, “but I think an employer as large as mine—a medical corporation—could do something for its employees, like my father had or like I once had.”

“It’s ultimately my private responsibility,” he adds “though I would very graciously accept something in the way of a subsidy along the medical line, and I would like my employer to say that good insurance coverage is part of the employment package.”

Virginia also doesn’t want to convey the impression that she feels as though she’s owed anything. “I don’t want people to think I want someone else to pay my bills,” she says. In her 28 years of marriage, she points out that she’s made calculated decisions—such as seeking part-time work so she could spend more time with her children—that reduced the likelihood of being offered employer-paid insurance.

But looking back at the havoc that medical bills have wreaked on the family’s finances, she says emphatically, “I would never tell anyone else to do it like this.”

“I would feel guilty using insurance if the rest of my family can’t.”