

## The Nelson Family, Louisville, Tennessee



*“Sometimes there was insurance, and sometimes there wasn’t.”*

Nobody needs to tell Patricia Nelson how important health insurance is. For much of their 14-year marriage, her husband, William, had to be hospitalized once or twice a year because he suffered from bipolar disorder. When he had insurance, he could receive treatment in private psychiatric hospitals. When he didn’t, he was forced to seek care at a state hospital. “The conditions there were very bad,” Patricia recalls. “Once, he watched a man kill himself.”

Then, when William was just 35 years old, he developed amyotrophic lateral sclerosis, also known as ALS, or Lou Gehrig’s disease. The former college football player and pre-med student with a charismatic personality and rugged

good looks, lost the ability to talk and feed himself. But the disability-linked insurance provided by Medicare meant that in the final months of his illness, Patricia could care for him in their own home, with doctors, nurses, and therapists stopping by as needed, at little cost to the family. “There’s no way I could have paid for his medical care,” she says with obvious gratitude.

Patricia, 44, has also seen the importance of insurance to her own health, and her 12-year-old son’s. When she’s had health insurance through her employers, it’s meant that she could get regular Pap smears, mammograms and dental care, and her son, Sam, could see specialists for his allergies and asthma as well as a congenital skin condition. When her employers haven’t provided health insurance, it’s meant either putting off care or piling up bills for emergency room treatments and hospitalizations. Patricia is still paying off a \$6,000 bill for one of Sam’s asthma-related hospitalizations, seven years after it occurred.

Despite Patricia’s understanding of the significance of insurance, she and Sam have been going without it since June 2000, one month after she left a job with health benefits to help a sister and brother-in-law strengthen their family business. They aren’t able to offer health insurance to their five employees, Patricia says, because their business, a convenience store and bakery, is struggling. Patricia looked into picking up the cost of her old policy herself, but it would have cost \$355 a month—or \$4,260 a year—way too much for her to afford on her annual income of \$27,000 from her job and Social Security survivors’ benefits.

### A costly lesson in what being uninsured means

Like many Americans, Patricia has found over the years that her family’s access to health insurance has depended largely on the decisions of employers. Because her husband usually worked in commission-based sales, where jobs rarely provide benefits, it was usually through Patricia’s employment that the family had health insurance. “That’s about the only way you can get affordable insurance, through an employer,” Patricia observes. But Patricia’s spotty experience with job-related health insurance demonstrates that one cannot even rely on that.

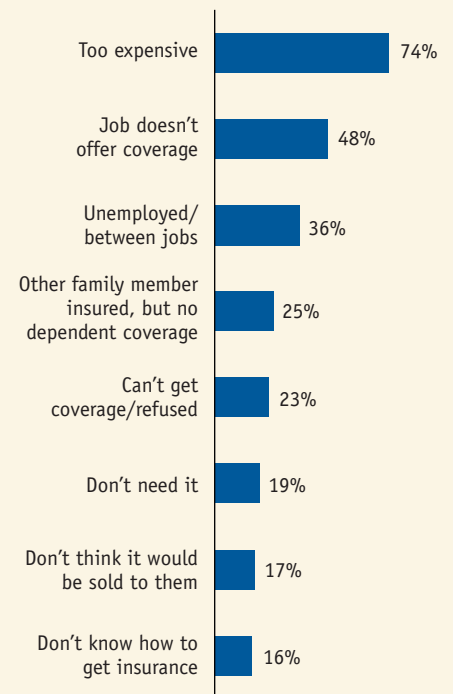
For 10 years, from 1983 through 1993, Patricia worked in a restaurant, making just above minimum wage. “Sometimes there was insurance, and sometimes there wasn’t, depending on who the owners were,” she says. “It changed hands three times while I was there.”

One of the periods during which Patricia’s former employer wasn’t offering health insurance was during Patricia’s 1987 pregnancy with Sam. “I saved up to pay to have him, and we had the money in the bank,” she says. “I remember it cost \$900 for the doctor and about \$1,800 for the hospital.”

Another of her uninsured periods coincided with Patricia’s need for crowns on four teeth. They cost her \$1,500.

### Uninsured Adults Cite High Costs as Reason

Percent Reporting



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

But the most costly uninsured medical expense came when Sam was five years old and had a bad asthma attack. "That attack just came out of the blue," Patricia recalls. "He was having trouble breathing, and I first took him to an emergency room. They told me he was OK, to just take him back home and give him a breathing treatment. So we headed back home, but he was breathing so loudly that I knew there was no way he was OK. We went back out, and this time we went to the pediatrician's office. By now, he was getting clammy,

and the nurse gave him a shot of epinephrine while the doctor called the ambulance. This time we went to Children's Hospital, and they put him right in intensive care."

At Children's Hospital, the billing office checked on whether Sam was eligible for Medicaid. Patricia remembers the family missing the eligibility cutoff by \$4. "We were in there for two days, and I ended up with a \$6,000 hospital bill that I'm still paying \$25 a month on," Patricia says. Her balance, after seven years of paying, is \$1,790.

Partly because of her discontent with the erratic benefits provided by the restaurant, soon after Sam's hospitalization Patricia found a new job as a kitchen manager for a hotel restaurant. The insurance kicked in 90 days after she went to work, with the employer pay-

ing the total cost of Patricia's coverage, and Patricia picking up the cost for Sam. "It was affordable," Patricia remembers of the insurance she bought for Sam. (By this time William was covered by Medicare, or the cost of a family policy would have been higher.) Patricia also took a second part-time job in a restaurant to help make up for the paycheck that the family had lost when William had to stop working.

Patricia stayed in the hotel job for a little more than two years, when she took a leave of absence to care for her husband during the last three months of his illness. He died in November 1995 in a hospital bed in the living room of the family's mobile home. Even though Medicare covered most of his bills, Patricia was left with a \$500 doctor's bill, and she knows that her husband's dentist simply wrote off hundreds of dollars worth of care.

### **Even with insurance, mounting medical bills**

After her husband's death, Patricia stayed home for 2 months to pull herself together and help Sam, then 7, cope with the death of his father. She decided she needed to look for a less stressful job than she had had at the hotel, even though she knew it might mean giving up her health insurance. "I had been working 60 or 70 hours a week," she says. "With William gone, I felt Sam needed me at home more than I could be if I was in that job."



***"Basically, I've just been hoping Sam doesn't get sick, and so far, it's worked."***

She returned briefly to the restaurant where she'd formerly worked, but the benefits were still in flux. A few months later she found a job with a grocery store chain that offered health insurance as a benefit. The job paid \$330 a week, and the insurance coverage it offered cost \$35 a week for both her and Sam. That meant that after deductions, Patricia was bringing home \$205 a week, or about \$900 a month. Fortunately, Patricia and her son each were also receiving Social Security survivors' benefits. "Otherwise," she says, "I don't know how we'd have made it."

Still, even with the Social Security benefits, keeping up with all their bills, including their uncovered medical costs, was difficult. Patricia was paying \$1,820 a year for insurance for herself and Sam, whether or not they ever went to see a doctor or dentist. If they did, they had to pay the \$400 in annual medical deductibles, \$100 in annual dental deductibles, and a co-pay of 20% on every bill. That meant that every time Sam needed a new inhaler, it cost Patricia \$8 or \$15, depending on whether it contained a generic drug. The co-pay for her annual physical, including a Pap smear and mammogram, came to \$160. And when Patricia needed two more crowns, her co-pay was \$500. Sometimes Patricia wondered whether she wouldn't have been better off using the money she was paying for insurance to pay her medical bills out of pocket. But then she'd remember the \$6,000 bill she was still paying for Sam's hospitalization in 1993.

Patricia knew other people who risked going without insurance because of the cost. Since she was a supervisor at the grocery store, she knew exactly how many of her employers opted to buy the insurance the company offered. "I had maybe 35 full-time employees, and less than half bought the insurance," she says. "None of the young people who were working there could afford it."

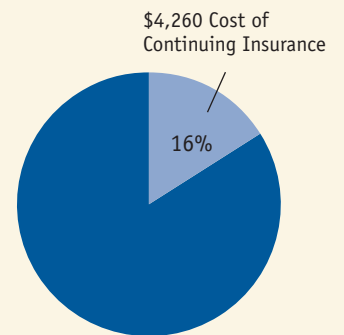
### Making a difficult choice

When Patricia's sister and brother-in-law asked her last spring to help them out in their new business, she had to think hard about the impact on her and Sam, since her relatives couldn't afford to offer her insurance. "Giving up my insurance was a big drawback, but I just felt like they needed me," she says. "They've only had the bakery for 10 months, and they're having a hard time getting organized. I felt I should be there helping them."

Patricia told her brother-in-law of her concerns about losing insurance coverage, and he offered to pay her bills if she or Sam became sick. "He would try," she says. "I know he would." But, having firsthand experience with the high cost of medical care, she doesn't view that as a promise her brother-in-law can necessarily keep. "If Sam ended up in intensive care again, one of us would end up in bankruptcy court," she says. "There'd really be no choice."

### Health Coverage Through COBRA\* for Nelsons Was too Expensive

\$27,000 Annual Income



\*Under COBRA, coverage is available to insured employees for 18 months after they leave a job, however they must pay the full premium plus a 2% surcharge.

Despite her misgivings over losing her insurance, Patricia decided to put her sister's and brother-in-law's needs first, and gave notice at her old job. Then she and Sam took full advantage of their last few months of insurance coverage. "Before we lost our insurance, I filled all the prescriptions," she says. "Sam had a growth removed, and we both went and got our teeth cleaned."

Because she's making a little more money at her new job and not paying for health insurance, Patricia is bringing home more money every week—\$247 instead of \$205, or \$1,062 a month instead of \$881. (The Social Security benefits provide another \$1,131 a month.) The extra money in her paycheck is helping her pay down some of the credit card bills she amassed during her husband's illness and during a couple of periods when a brother and her grown daughter (from a previous marriage) needed her help. Altogether, her fixed monthly expenses add up to \$1,600, including \$285 for rent on the trailer, \$358 for her car payment, \$100 for electricity, \$100 for telephone and cable TV, and \$85 for car insurance. After paying the bills that can't be ignored, she's left with about \$600 a month for everything else.

When the insurance coverage terminated on June 8, Patricia went into denial mode. "Basically, I've just been hoping Sam doesn't get sick, and so far, it's worked," she says. She feels confident that Sam would be able to get medical care even without insurance, because his longtime pediatrician has assured her of that. "He's that kind of guy," she says. "He's told me I never have to worry about whether he'll see Sam. Even for my co-pays, he's always let me pay when I can."

But the big worry is a hospital bill. "I know Children's wouldn't turn him away either, but I don't know how I'd pay them," she says.

With football season starting up soon and Sam eager to follow in his father's footsteps, Patricia recently purchased a nominal injury insurance policy that enables him to qualify to play. She knows that whatever coverage it provides would probably be inadequate, but, with all he's been through in his life, she doesn't want to deny him the opportunity to play. "I know that any time in the next two months he could end up in the hospital just from rolling around on a football field," she says. "There's all kinds of risks out there."

While she prays that she and Sam stay healthy and injury-free, Patricia is checking out her insurance options, because she definitely wants to be insured again. "I'm fixing to turn 45," she says. "I've been healthy my whole life, but none of us has any guarantees that we're not going to be sick tomorrow."

She's been told she might be able to buy TennCare coverage—Tennessee's alternative to Medicaid—for Sam for \$90 a month, but since few doctors in her county accept TennCare coverage, she doesn't see much point to it. She

### **Small\*, Low-Wage Firms Are the Least Likely to Offer Health Benefits**

Percent of Firms Offering Health Benefits



\*Small firms defined as having less than 200 employees.

Source: Kaiser/HRET Survey of Employer-Sponsored Health Benefits, 2000.

watches newspaper ads in the hopes of seeing an affordable insurance policy she could buy for herself and Sam. “The thing is, you can’t get private insurance for a price you can afford,” she says. After taking a recent call at her brother-in-law’s market from an insurance agent peddling policies to owners of small businesses, she’s persuaded her brother-in-law to sit down and listen to the sales pitch. “He says he’ll consider getting it for his employees if the price is right, but he says a lot of things,” she says. “It won’t necessarily come to pass.”

As she weighs her health insurance possibilities, she also has to balance them against a long-term goal: her determination that Sam, an honor student, will go to college and earn the degree his father had to forgo when illness forced him to drop out in his senior year. She knows that just a few years from now, when Sam turns 18, the family’s income will be cut in half as Social Security survivor’s benefits end. How will she pay her household expenses, let alone college tuition? “I’ll have to go back to working two jobs, I guess,” she says.



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